The Development of an Instrument to Evaluate Nursing Assistants' Knowledge, Skills and Attitudes within a Palliative Approach

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A thesis submitted for the degree of
Doctor of Philosophy

May 2018

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Western Sydney University

Acknowledgements

I acknowledge with special thanks, my principal supervisor Professor Esther Chang, and my co-supervisors, Associate Professor Amanda Johnson, Dr Anthony Good and Dr Michel Edenborough, for their guidance, encouragement and ongoing support. Each of my four supervisors contributed their particular strengths to the development of this thesis. Collectively they helped me to navigate the course of this research journey.

I acknowledge my husband Geza for 'holding the fort' and sons Laurence, Alexander and Theodore, my mother and my sisters Joanne and Clair, who were always there in the background. They gave me time, took on many tasks at home, and supported me. In the time that this thesis was in preparation, many other people also contributed their expertise and time. I would like to acknowledge the following from Western Sydney University for their guidance: Susan Mowbray, Academic Literary Adviser, who read several of my chapters and made valuable suggestions; Dr Russell Thomson and Dr Peter Jonason, who provided statistical and psychometric advice. Friends Manuela Vidal and Anne Prichard who were very supportive and those friends who provided friendship and encouragement in the research 'space' or stayed friends over the time that I was busy writing this thesis.

Finally, I would like to acknowledge all the study participants who made this research possible: care managers and directors of nursing, registered nurses, academics, and 'nursing assistants' who all gave their time, shared their views, and showed good will towards this project. In undertaking this study to design, develop and validate a new instrument to evaluate nursing assistants' knowledge, skills and

attitudes, the important contribution of nursing assistants in the provision of a palliative approach in RACFs is acknowledged.

Statement of authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I, Sara Karacsony, hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Date 31/05/2018

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Abbreviations

Abbreviation	Full term
AIN	Assistant in Nursing
CVAQ	Content Validation of Attitudes Questionnaire
CVI	Content Validity Index
CVKQ	Content Validation of Knowledge Questionnaire
CVSQ	Content Validation of Skills Questionnaire
DON	Director of Nursing
EN	Enrolled nurse
LPN	Licensed Practical Nurse
PANA	Palliative Approach for Nursing Assistants
PCQN	Palliative Care Quiz for Nurses
qPAD	Questionnaire on Palliative Care for Advanced Dementia
RACF	Residential Aged Care Facility
RN	Registered nurse
RTO	Registered Training Organisation
TAFE	Technical and Further Education

Abstract

Older people entering Residential Aged Care Facilities (RACF) have complex health care needs, with many requiring a palliative approach on admission. The focus of a palliative approach is on managing physical and emotional symptoms to reduce suffering, promote comfort, and enable a peaceful death. Providing this level of care however, requires essential knowledge, skills and attitudes in care processes.

'Nursing assistant' is the umbrella term used in this study to describe the largest aged care workforce. At present nursing assistants make up 70% of the RACF workforce, and are increasingly assuming more direct care of residents with limited supervision and support. Determining nursing assistants' knowledge, skills and attitudes to provide care with a palliative approach is particularly important given their level of involvement in care processes.

This study aims to develop a valid and reliable instrument capable of determining the training and development needs of nursing assistants providing a palliative approach in RACFs.

The development and testing of the instrument follows recommended psychometric processes and comprises four separate sequential phases, using a mixed methods approach. In Phase 1, items were generated from qualitative interviews with nursing assistants (n=25). In Phase 2, item content was validated with four groups of experts. In Phase 3, three separate questionnaires entitled PANA (Palliative Approach for Nursing Assistants) were pilot tested as a single instrument. In Phase 4, the psychometric properties of the new instrument were

evaluated using a random sample of 348 nursing assistants across 17 RACFs in the Greater Sydney region.

Individual item properties were analysed for difficulty, discrimination and item-total correlations, reducing the item set to 40. Psychometric testing included translational (face and content) and construct validity. Three separate questionnaires were finalised: the PANA_Knowledge Questionnaire, the PANA_Skills Questionnaire and the PANA_Attitudes Questionnaire. Internal consistency for the instruments ranged from α=0.81 to 0.74. Test-retest reliabilities using the intra-class correlation were in the range of 0.709-0.335 for the three instruments. Five discriminative and divergent hypotheses were made; four were supported.

The study's results show that experience in the role, rather than the level of education, results in higher knowledge and attitude scores across groups of nursing assistants, while their skills largely remain static. What emerges is an identification of the gaps and current educational shortfalls affecting nursing assistants' competence to deliver care with a palliative approach.

The PANA questionnaires demonstrate sensitivity for nursing assistants' level of education and scope of practice and, as such, are reliable tools by which to identify the educational needs of the largest cohort of the aged care workforce.

Chapter 1 Introduction

1.1 Overview

This introductory chapter outlines the context for this study. It provides a snapshot of the older person entering residential aged care facilities (RACFs), formerly known in Australia as nursing homes and hostels, and identifies their palliative care needs. A staffing profile of RACFs is provided, with a detailed overview of the roles and pre-service education of nursing assistants. The problems that are identified and the research question driving this study are then defined. The conceptual framework used to guide this research is introduced, with stress on the need for an instrument to evaluate workforce competency. The study's purpose and its significance are outlined. The chapter concludes with a definition of terms used throughout this thesis and an overview of the following chapters.

1.2 Older People Admitted to RACFs

Many older people requiring permanent placement in RACFs are admitted with high care needs when they are at a stage of frailty and in the advanced stages of their illness or disability (Australian Institute of Health and Welfare, 2017). A diagnosis of dementia, and a long (eight weeks or more) hospital stay are risk factors for admission to RACFs (Australian Institute of Health and Welfare, 2016). Older people who are receiving palliative care in hospital are also twice more likely to be admitted to an RACF than other patients (Australian Institute of Health and Welfare, 2016).

While death is not necessarily imminent, RACFs were identified over a decade ago as the 'slow stream hospices of the future' (Abbey, Froggatt, Parker, & Abbey, 2006) and the final place of care for many older people (Cooper & Glaetzer, 2004; Kristjanson, Walton, & Toye, 2007; Phillips, Davidson, Jackson, et al., 2006). In 2015, 34% of all registered Australian deaths occurred in RACFs, compared to 26% in 2010 (Australian Institute of Health and Welfare, 2016; Broad et al., 2013). The majority (78.4%) of permanently placed residents die in RACFs. During 2013–14, 35% of all RACF deaths occurred in less than one year (n=9,133) and 5% in less than one month (n= 2,973) (Australian Institute of Health and Welfare, 2016). The uncertainty of the death trajectory for many residents in this setting has been identified as a major challenge for providers of care in RACFs (Barclay et al., 2014). To enhance older peoples' quality of life as they approach the end of life, a palliative approach is a recognised framework for the RACF setting.

1.3 A Palliative Approach

A palliative approach is the term widely used in Australia to describe the provision of palliative care to older people in RACFs. The term corresponds to National *Guidelines for a Palliative Approach in Residential Aged Care* (Australian Government Department of Health, 2006), a toolkit resource for the RACF workforce developed from these *Guidelines* (University of Queensland/Blue Care Research & Practice Development Centre, 2012), as well as a unit of competency: *Deliver care services using a palliative approach* for nursing assistants endorsed by the Community Services and Health Industry Skills

Council (2013), the peak national advisory body on skills and workforce development. This is the terminology used in this thesis, acknowledging the decision by Palliative Care Australia to focus on the term palliative care in the revised Australian National Palliative Care Standards (PCA, 2018) consistent with the WHO definition that all people who are dying can benefit from palliative care.

A palliative approach aims to relieve pain and unnecessary suffering by adopting comfort-focused measures and clarifying the goals of care around ongoing treatments such as dialysis, and the need for hospitalisation (Australian Government Department of Health, 2006). Ideally applied early in the disease trajectory, a palliative approach is especially relevant for older people who may experience a longer dying trajectory associated with frailty, chronic life-limiting illnesses, and gradual decline in function (Australian Government Department of Health and Ageing, 2006; World Health Organisation, 2004). Moreover, for many older people entering RACFs, a palliative approach is often required on admission to deliver person-focused, high-quality care as the person transitions to end of life care. In light of the palliative care needs in this setting (Hermans, Cohen, Spruytte, Van Audenhove, & Declercq, 2016), RACF staff at all levels need to be able to provide care with a palliative approach to identify and communicate changes in the illness trajectory, manage physical and emotional symptoms, and provide end-of-life care. This, however, requires essential knowledge, skills and attitudes in care processes.

1.4 **The RACF Workforce**

The RACF direct care workforce comprises registered nurses (RNs), enrolled nurses (ENs) and nursing assistants. Various occupational titles describe the work of nursing assistants, including assistants in nursing (AIN), care assistant/companion/staff/workers, care service employees and personal care assistant/care workers; these are not professional titles. With the exception of certified nursing assistants in the United States, this workforce in aged care is neither professionally regulated nor accredited. In this study, the umbrella term 'nursing assistant' is used to encompass the various occupational titles associated with this role, as nursing assistants work under the supervision of RNs and ENs who assume overall responsibility for the direct care of residents in aged care (Australian Government Department of Education and Training, 2013).

Of the 235,764 direct care workers employed in Australian RACFs in the 2016 workforce survey, 70% (n= 108,126) were nursing assistants, 15% (22,455) RNs and 10% (n=15,697) ENs (Mavromaras et al., 2017). Employment for nursing assistants in both residential and community aged care has risen strongly over the last ten years, with projected job openings by 2020 of over 50,000 (Australian Government Department of Employment, 2016). Most of the growth in the direct aged care workforce correlates to the growth in the number of nursing assistants, which has been the trend since 2003 (Australian Government Productivity Commission, 2011; Mavromaras et al., 2017,).

While the number of nursing assistants has steadily increased across residential

aged care (7,814 since 2012) to 70%, the ratio of RNs has remained unchanged since 2012 at 15% while EN numbers have declined by 2% (n=1, 218) (Mavromaras et al., 2017). A recent New South Wales Parliamentary Enquiry (Parliament of New South Wales, 2016) determined not to support the existing legal requirement for RNs to be present 24 hours across seven days per week in NSW RACFs. Until this time, New South Wales was the only Australian state where minimum staffing and the requirement to have an RN on site was legislated (Australian College of Nursing, 2016b). Not all aged care providers agreed with this decision, as one of its implications is reduced supervision of nursing assistants.

1.5 **Nursing Assistants' Role**

Nursing assistants have varying tasks within their role, including providing routine personal care such as bathing, dressing, or grooming, and assisting elderly, convalescent or disabled people with eating, mobility and communication, either in their own homes or institutions (Australian Government Department of Employment, 2016). Nursing assistants are required to report observations about any changes in a resident's physical or mental status to an RN. They are also required to participate in the implementation of individualised care plans.

The person-focused nature of the nursing assistants' role means that they provide most of the direct, supportive care to residents, form close personal bonds and often know more about the residents' preferences and wishes than RNs (Parker, Clifton, & Tuckett, 2011). Nursing assistants are broadly reported

as having a key role in observing behaviours, and are often the first to detect the physical and psychosocial symptoms commonly associated with the end of life (Åhsberg & Carlsson, 2014; Fryer, Bellamy, Morgan, & Gott, 2016; Holloway & McConigley, 2009; McClement, Wowchuk, & Klaasen, 2009b). While the provision of care by nursing assistants is considered appropriate in situations in which the person receiving care has few comorbidities and whose health status is stable (Australian College of Nursing, 2016a), a range of clinical care is provided in RACFs. The complexity of the older person's needs including rising rates of dementia and concomitant behavioural and psychological symptoms of dementia is evidenced by the proliferation of units of competency in community services training packages (Community Services and Health Industry Skills Council, 2015). Despite these, nursing assistants are reported as undertaking tasks beyond their scope of practice. The National End of Life Care Program (2011) produced by the Royal College of Nursing (Henderson, Willis, Xiao, & Blackman, 2016). Increasingly they are involved in clinical practices, provide medications, perform clinical assessment tasks (including monitoring and observing to identify unwell residents) and assist in establishing therapeutic interventions to improve care (Ray, Dassa, Maier, Davis, & Ogunlade, 2016; J. Williams, Stolp, Roberts, Fearn, & Doyle, 2016). Nursing assistants are also often involved in delivering bad news to families (Frey, Boyd, Foster, Robinson, & Gott, 2016). Undoubtedly, within RACFs, nursing assistants are the largest aged care workforce, providing most direct care to older people with palliative care needs.

As noted, nursing assistants are not professionally registered, despite the

Australian Nurses Federation and some aged care providers arguing for professional registration for this group. In response to the Caring for Older Australians Inquiry (Australian Government Productivity Commission, 2011), the Federation argued that accreditation would provide benchmark education and make nursing assistants accountable for their practice, promote more consistent skill outcomes, and reduce the supervision burden of RNs.

Key counter-arguments presented in the inquiry to support non-regulation included the nature of nursing assistants' work being primarily personal care and not health care. Regulation of this group of personal care workers would warrant similar licensing of other providers of personal care such as child care workers, who do not provide any health care services; and accreditation might deter workers who did not want to pursue formal education, resulting in the non-compliance of some current RACF workers (Australian Government Productivity Commission, 2011). Additionally, the imposition of a licensing regime on nursing assistants would likely exacerbate the workforce shortages often experienced in the aged care sector, especially in rural and regional areas (Deloitte Access Economics, 2016).

Because there is no regulatory requirement for nursing assistants to participate in pre-service education or training, they are not targeted for professional development (Martyn, 2016a). This is an Australian requirement for RNs and ENs (Australian Institute of Health and Welfare, 2016). Apart from education related to workplace policy and legislation, nursing assistants' education is limited, ad hoc and does not necessarily address their educational needs

(Martyn, 2016a). In regional and remote areas of Australia, a lack of access to training is also reported (Mavromaras et al., 2017). While there is variation across countries in the level of education, training and qualifications obtained, nursing assistants in Australia generally possess vocational qualifications to the level of Certificate III and, to a lesser extent, Certificate IV and experience the shortest training period (Australian Government Productivity Commission, 2011; Mavromaras et al., 2017; United Kingdom Department of Health, 2008; United States Department of Labor, 2013). With the majority of permanently placed RACF residents requiring high level care (Australian Institute of Health and Welfare, 2016) and a palliative approach, it can be argued that nursing assistants are underqualified for the expectations of their role.

1.6 Educational Preparation

Certificates III and IV are the most common level of educational attainment and account for 41.7% of qualifications held by this group (Australian Government Department of Employment, 2016): two thirds of the facilities that participated in the National Aged Care Workforce Census and Survey 2016 reported that more than 75% of their nursing assistants held the Certificate III in Aged Care (Mavromaras et al., 2017).

1.6.1 Certificate III/IV in Aged Care

The Certificates in Aged Care were developed by the Community Services and Health Industry Skills Council (2013), the peak national advisory body on skills and workforce development. Technical and Further Education (TAFE) colleges, the largest vocational education provider, teach the certificates III/IV and

registered training organisations (RTO) provide training packages to aged care organisations in the form of workshops and self-directed learning packages.

Certificates III and IV in Aged Care were superseded in 2015 by Certificate III in Individual Support and Certificate IV in Ageing Support, as part of ongoing review processes. Amendments to these certificates addressed concerns about the variability in the content and duration of courses being offered by RTOs, the processes of skills and competency assessment, and the validity of the educational outcomes (Australian Government Productivity Commission, 2011; Australian Skills Quality Authority, 2013). On review in 2015, 120 hours of fieldwork was made compulsory within the certificates to better prepare students for the work environment (Australian Government Department of Education and Training, 2016b; Australian Skills Quality Authority, 2013; Thorne, 2015).

In Australia there is an industry expectation that nursing assistants attain the Certificate III in Aged Care (Individual Support) within a specified time frame as this is the recognised entry-level qualification for employment in the aged care sector. As stated, 75 %, or two-thirds of nursing assistants surveyed in 2016, held the Certificate III in Aged Care, which was an increase from 62% in 2012 (Mavromaras et al., 2017). However, not all nursing assistants possess this qualification when entering the workforce.

Until the review of Certificate III from Aged Care to Individual Support in 2015, one of the ten core units provided in Aged Care was a unit of competency: *Deliver care service using a palliative approach*. This is now an elective unit in

Certificate III in Individual Support, the entry level qualification for aged care services, and a core unit in Certificate IV in Ageing Support (Australian Government Department of Education and Training, 2016c). Certificate IV was held by only 1-–24% of nursing assistants in just over half (56%) of the RACFs in the National Aged Care Workforce Census and Survey 2016 (Mavromaras et al., 2017). Paradoxically, the reprioritising of core units is in contradiction to the importance of palliative care as rated by workers, who consider it one of the three most valuable areas of training (Deloitte Access Economics, 2016; Mavromaras et al., 2017).

1.6.1.1 Deliver Care Services Using a Palliative Approach.

Within the unit of competency, *Deliver care services using a palliative approach*, six elements are introduced that describe the essential knowledge and skills required by nursing assistants: 1. applying the principles and aims of a palliative approach when supporting individuals; 2. respecting the person's preferences for quality of life choices; 3. following the person's advance care directives in the care plan; 4. responding to signs of pain and other symptoms; 5. following end-of-life care strategies; 6. managing own emotional responses and ethical issues (Community Services and Health Industry Skills Council, 2015). It is not clear, however, how evaluation of nursing assistants' palliative care knowledge is undertaken; nor is it known if nursing assistants at Certificate level III have necessarily completed this unit. There are certainly indications that not all nursing assistants employed in RACFs have Certificate level qualifications, or have attended professional development in palliative care (Frey, Boyd et al., 2016; Mavromaras et al., 2017; Mitchell, Nicholson,

McDonald, & Bucetti, 2011; Phillips, 2008; Ronaldson, Hayes, Carey, & Aggar, 2008; Walker, 2007).

1.6.2 Graduating attributes

As well, the graduating attributes of nursing assistants have been found to vary. Martyn (2016a) found that the pre-education curricula of nursing assistants varied in content and that ongoing professional development education was not optimally aligned with the demands of the workplace. Because RTOs cover different content in the curricula of the certificates they provide, nursing assistants have different learning experiences, graduating attributes and skill levels (Martyn, 2016a). This means that nursing assistants, as a broad-based group, may not all be delivering the same standard of care. As already discussed, there is no specific prior learning, essential skill training or mandatory requirement to participate in pre-service education, and nursing assistants are less likely than RNs or ENs to attend non-mandatory professional development education. Of the nursing assistants (n= 108,126) surveyed in the National Aged Care Workforce Census and Survey 2016, only 7.4% reported a specialised qualification in palliative care although 72% identified this as a priority area for training (Mavromaras et al., 2017).

1.7 Research problem

Nursing assistants are the largest aged care workforce, providing direct care to older people in RACFs, most of whom are admitted in advanced stages of illness or frailty, with complex health care needs (Australian Institute of Health and Welfare, 2016). As a result of this admission pattern, many older people now

require palliative care interventions on admission. The shift in recruitment in nursing assistants as the mainstay of the RACF workforce, with fewer RNs in a supervisory role, requires nursing assistants to have a range of competencies to ensure they can provide a high level of care as the older person transitions to end of life. Optimum care in the end-of-life phase has the potential to reduce the suffering of the older person and mitigate the anxieties and grief of family members (Frey, Foster, Boyd, & Gott, 2017). Workforce competence and confidence, in providing a palliative approach in the RACF setting, is likely to enable the older person to die in a familiar place with familiar people with whom bonds of affection may have developed. Undoubtedly, nursing assistants are well placed to identify and support residents' physical, psychological, emotional and spiritual needs (which are key elements of a palliative approach) if they have the pre-requisite knowledge, skills and attitudes.

Key elements of a palliative approach are introduced in the unit *Deliver care services using a palliative approach* but concerns about variability in the content and duration of vocational courses, processes of skills and competency assessment, and differences in learning experiences and graduating attributes have been reported (Australian Government Productivity Commission, 2011; Martyn, 2016a). To determine nursing assistants' knowledge, skills and attitudes to providing care with a palliative approach is particularly important given their level of involvement in aged care processes and the reported lack of ongoing educational opportunities (Martyn, 2016a).

1.8 **Conceptual Framework for a Palliative Approach in RACFs**

National strategies have focused on improving the quality of palliative care older people receive in RACFs by providing education and training to the aged care workforce, developing practice and building palliative care competence (Australian Government Department of Health, 2008; Australian Government Department of Health and Ageing, 2006; Kelly, Ersek, Virani, Malloy, & Ferrell, 2008; Parker, 2014; University of Queensland/Blue Care Research and Practice Development Centre, 2012; L. Williams et al., 2016).

In Australia, the first evidence-based *Guidelines for a palliative approach in residential aged care*[1] were introduced as framework in 2004 and revised in 2006 (Australian Government Department of Health, 2006). They were distributed to RACFs across Australia, accompanied by online training resources (Palliative Care Australia, 2006). The National Palliative Care Strategy (Australian Government Department of Health, 2010) supported the implementation of palliative care education in RACFs through educational resources and programs. These included incorporating *Deliver care services in a palliative approach* as a mandatory educational unit in the former Certificate III in Aged Care, which, as mentioned previously, has been superseded by the Certificate in Individual Support in which the unit is offered as an elective only (Community Services and Health Industry Skills Council, 2015). In 2012 the Residential Aged Care Palliative Approach Toolkit, a comprehensive evidence-based resource including policies, procedures and education modules, was

[1] *Guidelines* henceforth

rolled out nationally to RACFs. The toolkit translated the evidence from the *Guidelines for a Palliative Approach in Residential Aged Care* and 'Pain in Residential Aged Care Facilities: Management Strategies', developed by the Australian Pain Society (University of Queensland/Blue Care Research & Practice Development Centre, 2012). The *Guidelines,* therefore, underpin policy, process and education in RACFs as a conceptual framework.

1.9 International Trends

In the United Kingdom, similar national strategies were developed under the End of Life Care Strategy by the Department of Health (2008) to improve education and training in the aged care workforce. The *Fundamentals of nursing care at the end of life* (2015) produced by the Royal College of Nursing is a guide that highlights key nursing contributions and processes across different healthcare settings. The United States, however, leads the way in interventions for improving palliative care for older people in RACFs (Hall, Kolliakou, Petkova, Froggatt, & Higginson, 2011) as well as in palliative care nursing education. The End-of-Life Nursing Education Consortium (Ferrell et al., 2005), initiated in 2000, was designed to advance nursing's role in palliative care and educate nurses about end-of-life care with a 'train the trainer' strategy. To disseminate palliative care education to nursing assistants in geriatric settings, its core curriculum for nurses was merged with the Palliative Care Educational Resource Team's program designed for nursing assistants (Kelly et al., 2008).

1.10 Core competencies in palliative care

Nursing assistants may have different learning experiences, graduating

attributes and skills levels; however, core competencies in a palliative approach have been widely advocated for all health and social care workers including nursing assistants (Gamondi, Larkin, & Payne, 2013).

In Europe, a White Paper written under the auspices of the European Association of Palliative Care outlined ten core palliative care competencies, designed to provide a common language for the provision of palliative care irrespective of setting, field or role (Gamondi et al., 2013). These core competencies indicate the knowledge, skills and attitudes that enable providers of care to meet the needs of patients and families in the setting where they are receiving care. While these competencies were designed for health and social care workers in Europe, they have broad applicability to providers of palliative care across disciplines and settings of care. They are specifically designed to include nursing assistants working in RACFs who do not possess tertiary qualifications in a health discipline. When viewed alongside Australian national standards in (Palliative Care Australia, 2018) and *Deliver care services using a palliative approach* (Community Services and Health Industry Skills Council, 2015), these core competencies provide useful and relevant benchmarking criteria for nursing assistants' learning and development needs.

As an indication of the importance of palliative care knowledge, skills and attitudes being integrated into practice across the different disciplines, core competencies in palliative care are being embedded into the curricula of all health professionals in Australia, notably through the Palliative Care Curriculum for Undergraduates (PCC4U) (Australian Government Department of Health,

2014). These core competencies are designed to prepare graduates to deliver care with a palliative approach and are based on four core capabilities identified as being integral for the provision of palliative care: i) effective communication in the context of loss, grief, existential concerns, and changing goals of care; ii) respect and appreciation for human responses throughout the illness trajectory; iii) understanding the principles for assessment and management of clinical and supportive care needs; and iv) capacity for self-reflection and evaluation of cumulative experiences on self and others. These align with the European Association's competencies and the key elements outlined *Deliver care services using a palliative approach*.

1.11 **Evaluation of knowledge, skills and attitudes**

For health professionals across different specialties, evaluation of palliative care education is an integral component of the learning process, and, in itself, evaluation is able to promote learning as well as determine the quality of educational processes (Perieira, 2006). Instruments used in evaluation can be tailored to the specific learning and assessment needs of the target group. Identifying a suitable instrument for use in evaluating the knowledge, skills and attitudes of nursing assistants who are not health professionals has yet to be determined.

1.12 **Study purpose**

One aspect of this study is to examine what instruments have been used to evaluate nursing assistants' knowledge, skills and attitudes in a palliative approach and to determine the suitability of these for nursing assistants' very

varied levels of education. The lack of such an instrument was, in fact, the impetus for this study.

The purpose of this study is threefold:

- to examine existing instruments that have been used to evaluate nursing assistants' knowledge, skills and attitudes when providing a palliative approach;
- to evaluate the development of existing instruments used to measure nursing assistants' scope of practice;
- to design, develop and validate an instrument for evaluating nursing assistants' knowledge, skills and attitudes within a palliative approach.

1.13 **Significance of study**

Nursing assistants constitute 70% of the RACF workforce in an aged care industry that is a major contributor to the comfort and quality of life of older people, yet little has been done to evaluate their needs or performance, and there are few documented processes for determining and evaluating their learning and development needs. The growth of this industry is forecast to be considerable, and increasingly, nursing assistants are assuming more of the direct care of residents with less supervision and support. Despite their critical role in providing care to people as they approach the end of life in RACFs, determining their knowledge, skills and attitudes within a palliative approach, appropriate to their level of education and scope of practice, has yet to be done.

The significance of this study is in the development of an instrument capable of

this evaluation, as a means of ensuring nursing assistants have adequate education, training and support to deliver optimum palliative care in line with workplace responsibility and demands, and their increasing scope of practice.

1.14 Definition of terms

Attitudes consist of how we feel, what we think and what we are inclined to do about something. Attitudes are influenced by cognitive information, affective or emotional information, and information concerning behaviour (Zanna & Rempel, 1988). A positive attitude to a palliative care approach is necessary for adopting the core values of palliative care.

Certificate III in Aged Care/Individual Support is a nationally recognised qualification developed by the Community Services and Health Industry Skills Council, designed for employment primarily in aged care; it provides a competency skill set based on performance criteria.

Knowledge in this study refers to the identification of foundation knowledge required for nursing assistants' level of education and scope of practice in relation to a palliative approach. Other knowledge that is also relevant to nursing assistants includes personal, lay, or tacit knowledge, which is knowing a person as an individual (Liaschenko & Fisher, 1999).

A palliative approach is a term that has been used widely in Australia in the context of residential aged care and to distinguish non-specialist or generalist palliative care provision from specialist palliative care. A core set of knowledge and skills is required by all health care professionals if they are to be able to

provide palliative care as an approach across a range of different health care settings (Palliative Care Australia, 2018).

Residential aged care facilities (RACFs) are regulated accommodation that provides hospitality services: accommodation, and personal and nursing care, to older people who can no longer live at home. Known formerly as nursing homes or hostels, RACFs provides two types of care: permanent and respite. An assessment determines the type and level of care a person is able to obtain (Australian Institute of Health and Welfare, 2017).

Skills denote competency in given tasks. They underpin effective performance and are the basis of employment. Nursing skills can be taught—physical assessment skills, e.g. assessing a person's skin integrity—and enhanced by psychosocial skills such as listening.

Specialist palliative care service provision*:* a specialist palliative care team or practitioner offers specific input on the assessment and treatment of complex symptoms, as well as advice and information on ethical, family, psychological or existential issues. Such a service builds on the palliative approach offered by primary care providers and is designated as one of three levels of service provision according to Australian national palliative care standards (Palliative Care Australia, 2018).

1.15 Preview of following chapters

This chapter has established the context for this research and the background to the research problem. The significance of the study to be undertaken has

been explained and the study purpose outlined. Subsequent chapters build on this chapter.

Chapter 2 reviews the literature to identify the instruments that have been used to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach. The strengths and limitations of these instruments are critically evaluated for their facility in delineating nursing assistants' levels of education and scope of practice.

Chapter 3 is divided into two sections. The first examines the methodology and study design used to conduct the research; the second section describes the conceptual framework for a palliative approach to guide the development of the new instrument. The chapter outlines the four phases of the study to design, develop and validate an instrument to evaluate nursing assistants in the context of a palliative approach.

Chapter 4 describes the data collection and analysis methods used in **Phase 1** to generate initial items. The processes of data extraction, and how items were generated within categories, are presented. The chapter also outlines the ethical considerations, strengths and limitations of the qualitative method, and how rigor was applied in this qualitative first phase.

Chapter 5 reports on the content validation process using the content validation index method in **Phase 2** of the study. The results of two rounds of content validation to develop the instrument are included and the final items for inclusion in the new instrument are detailed.

Chapter 6 reports on the data collection and analysis of the pilot test of the draft instrument in **Phase 3,** using both paper and online data collection. The setting and sample, including three groups of nursing assistants (n=61) in two RACFs, is discussed. The study's hypotheses are tested, and the results of the overall usability of the new instrument, as well as provisional findings on the instruments' performance, are discussed.

Chapter 7 reports on the data collection, analysis and psychometric evaluation following larger-scale field testing of the instrument across 17 RACFs in Greater Sydney, **Phase 4** of the study. The results of individual item analysis and the specific study-related hypotheses are presented, as are the indices testing the instrument's reliability and validity.

Chapter 8 is a discussion of the overall findings of the research and the implications of the study for research, education and practice. The limitations of the study and recommendations for further research in this field are also considered.

Chapter 2 Literature Review

2.1 Overview

The purpose of this literature review is to examine what instruments have been used to evaluate nursing assistants' knowledge, skills and attitudes within this approach. The chapter is divided into two: in the first section, the instruments used in evaluation processes are identified. This section presents the methods— including specific search strategy, inclusion and exclusion criteria— and the results of this search. In the second section, the strengths and limitations of each instrument are critically evaluated to determine their relevance for nursing assistants' level of education and scope of practice.

2.2 Aims

The literature review aims to:

1. identify what instruments have been used to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach in RACFs;
2. critically examine the development processes of existing instruments;
3. discuss and evaluate the strengths and limitations of these instruments for nursing assistants' level of education and scope of practice when caring for residents with palliative care needs in RACFs.

2.3 Methods

2.3.1 Search strategy

The search was conducted using the databases of the Cumulative Index to

Nursing and Allied Health Literature Plus with Full text, the Cochrane Library, the Joanna Briggs database, MEDLINE, PubMed, Scopus and Web of Science. In addition, a search of relevant Australian theses was conducted through TROVE.

Medical Subject Headings relevant to each database were used along with keywords. Boolean operators 'AND' and 'OR' were used to link search terms. Articles were restricted to those published in English from 2004–2017, as this timeframe incorporates the educational and training initiatives for the aged care workforce in the residential aged care setting established in Australia (Australian Government Department of Health, 2008; Australian Government Department of Health and Ageing, 2006). In addition, bibliographic references from identified literature were examined.

All references (n=738) from the search strategy were imported into EndNote Version 7 software. Duplicate references (n=137) were removed and the titles and abstracts of the remaining studies were evaluated against the inclusion criteria. Table 1 provides an example of the full electronic search strategy used for the CINAHL database.

Table 1

Search strategy

Terms for nursing assistants **and**	Terms for a palliative approach **and**	Terms for Tools
All combined with **or** (MM Nursing Assistants) Care Assistants OR Care Staff OR Care Workers (MM Nursing Home Personnel/nursing home employees) Personal Care Workers	All combined with **or** MM Palliative Care MM Terminal care End of Life Death OR Dying	Measure Instruments Tools (evaluation) Questionnaire

2.3.2 Inclusion criteria

The inclusion criteria consisted of the above terms to be eligible for this review. Studies identified for inclusion had to include the use of an instrument to evaluate nursing assistants' knowledge of, skills in, or attitudes towards a palliative approach in the residential aged care setting. Qualitative, quantitative and mixed methods designs were all eligible for inclusion.

Studies with mixed samples from which nursing assistants' data could be extrapolated were also included, as few studies focused exclusively on nursing assistants. The total number eligible for inclusion was 738.

2.3.3 Exclusion criteria

Studies in which instruments were used to measure specific palliative care frameworks or curriculums were excluded.

2.3.4 Results

The results of the search strategy initially identified **738** articles. These were reviewed by title and abstract for content related to the inclusion criteria. The majority of articles were excluded (n=726) as they did not relate to the specific aims of the search strategy, leaving a total of **12** articles identified as eligible. Articles that met the inclusion criteria were read in full. References to **seven** instruments were cited by 12 authors. The seven instruments were evaluated for their development, structure and psychometric properties, and their application to nursing assistants' level of education and scope of practice.

2.3.5 Instrument overview

Of the seven instruments cited by the 12 authors, two instruments measured knowledge of palliative care (Ford & McInerney, 2011; Pfister, Markett, et al., 2013; Pitman, 2013; Ronaldson et al., 2008); a third evaluated palliative care knowledge and practices (Thompson, Bott, Boyle, Gajewski, & Tilden, 2011; Unroe, Cagle, Lane, Callahan, & Miller, 2015); a fourth evaluated self-efficacy in providing a palliative approach (Phillips, Davidson, Ollerton, Jackson, & Kristjanson, 2007; Phillips, Salamonson, & Davidson, 2011); the fifth evaluated death, dying, end-of-life palliative care and interdisciplinary practice (Leclerc et al., 2014); the sixth measured palliative care for advanced dementia (Long, Sowell, Hess, & Alonzo, 2012); and the seventh measured self-perceived skills and knowledge in providing end-of-life care (Nochomovitz et al., 2010).

Of the seven instruments, only one was developed in Australia (Eager et al., 2003) and was validated in part as the Palliative Care Self-efficacy Scale

(Phillips et al., 2011). Two were developed in Canada (Leclerc et al., 2014; Ross, McDonald, & McGuinness, 1996), three in the United States (Long et al., 2012; Nochomovitz et al., 2010; Thompson et al., 2011) The remaining instrument was developed in Germany (Pfister, Muller, Muller, Core, et al., 2011).

The Palliative Care Quiz for Nurses (PCQN) (Ross et al., 1996) was used in three of the studies conducted in Australia (Ford & McInerney, 2011; Pitman, 2013; Ronaldson et al., 2008). One Australian study (Pitman, 2013) used an amalgam of three instruments: Tool 2.1 (Eager et al., 2003), the PCQN, and the End of Life Nursing Education Consortium Test (Kelly et al., 2008)—which was also used as a component of the Comfort Scale (Nochomovitz et al., 2010).

2.4 Instruments: Strength and Limitations

The development processes of the seven identified instruments presented in Table 2 were critically examined and evaluated in terms of their strengths and limitations in their capacity to elicit nursing assistants' knowledge, skills and attitudes within a palliative approach.

2.4.1 The Palliative Care Quiz for Nursing (PCQN)

The PCQN quiz is a validated instrument, developed in 1996 in Canada by Ross et al. to test nurses' knowledge of palliative care. It includes 20 items in a True/False/Don't Know format. The quiz was developed with qualified nurses and undergraduate nursing students, with the aim of testing knowledge, stimulating discussion and identifying misconceptions about palliative care nursing. Three conceptual categories are identified: the philosophy and

principles of palliative care, psychosocial and spiritual care, and symptom management. The instrument takes 20 minutes to complete.

The PCQN has been used to evaluate nursing assistants' knowledge of palliative care in several Australian studies by Ford & McInerney (2011), Pitman, (2013) and Ronaldson et al., (2008) and has also been used internationally with nurses in the UK (Hughes, Parker, Payne, Ingleton, & Noble, 2006) and (Proctor, Grealish, Coates, & Sears, 2000), and in the United States (Raudonis, Kyba, & Kinsey, 2002). The Kuder-Richardson (KR-20) formula, a reliability measure for dichotomous variables (Field, 2009), was used to assess the reliability of this test. The internal consistency of the quiz when first administered was 0.78; and for test-re-test reliability, the correlation coefficient between time 1 and time 2 was 0.56. Inter-item correlations were reported as positive and above 0.20. An analysis of variance comparing RNs, registered practical nurses or licensed practical nurses (equivalent to ENs in Australia), nursing students, and post-RN students identified significant differences between the groups using a post-hoc Scheffé's procedure (F=93 8, df=3, p=0 000).

In studies where the PCQN had been used, the results of participant groups correlated with their level of education and palliative care experience (Proctor et al., 2000). Ronaldson et al. (2008) found that nursing assistants with a Certificate III in Aged Care obtained higher scores than those without, and so did those participants who had experience in palliative care than those without.

Nursing assistants tested with the PCQN demonstrated palliative care knowledge described as equivalent to that of ancillary staff, which raised

concerns about their ability to assess, respond and refer residents for symptom management (Ford & McInerney, 2011; Ronaldson et al., 2008). The reasons for this low level of knowledge as measured by the PCQN is likely to stem from the instrument's development, which drew on clinical terms and an understanding of physiological processes and pharmacological knowledge expected of RNs: a high level of health literacy is required by respondents. Using the criteria employed by Ross et al. (1996, p. 127) in designing the quiz, the 'ecological validity'—content that nurses are likely to encounter in their practice—is beyond nursing assistants' current scope of practice and beyond what they could be expected to learn in their vocational entry level qualifications for the work place, or in continuing professional development targeted to their needs. This limitation is acknowledged by Ford and McInerney (2011).

Additionally, knowledge of the broader context of a palliative approach—providing care to a frail, aged population with different palliative care needs to those of people dying of cancer—is not captured in the PCQN (Australian Government Department of Health and Ageing, 2006), which was developed before the recognition of the palliative care needs of older people with complex, chronic diseases formalised by the World Health Organisation (Davies & Higginson, 2004).

2.4.2 The German Bonn Palliative Care Knowledge Test

The German Bonn Palliative Care Knowledge Test (Pfister, Markett, et al., 2013) was developed to measure health care professionals' knowledge and efficacy in palliative care. It consists of 38 items, 23 knowledge items and 15 specific self-

efficacy items. The knowledge domains are medicine, care, and psychosocial care. Items are rated on a 4-point Likert scale. The authors report that the instrument has shown sensitivity to change in pre/post testing following palliative care training, without ceiling effects. On initial testing, the Cronbach's alpha for knowledge was 0.71, and 0.86 for the self-efficacy portion of the test. Time for completion was less than ten minutes. A non-parametric Mann–Whitney U test was used to compare item differences between the sample group and the expert group. Multivariate analyses and a Pearson's correlation analysis were used to explore relationships between scores and demographic information. Results showed low knowledge by nursing home staff overall, with only 52.8 % correct answers. Nursing assistants accounted for at least 31 % of the sample.

Brevity is a strength of this instrument, but items were drawn from the PCQN, the Palliative Care Knowledge Test (Nakazawa et al., 2009) and the Test Instrument for Palliative Care (Adriaansen & Achterberg, 2004), all of which were designed for nurses and used RNs, ENs and nursing students—no nursing assistants—in its development processes.

2.4.3 Tool 2.1 Palliative Care Providers

Tool 2.1 Palliative Care Providers belongs to a compendium of instruments designed to evaluate palliative care projects. Tool 2.1 is designed to assess clinicians' degree of confidence in engaging in patient and family interactions at the end of life (Eager et al., 2003). Measures developed by Strumpf (2004) and Weissman, Ambuel, Norton, Wang-Cheng and Schiedermayer (1998) informed

the development of this tool. The first section, Attitudes towards Palliative Care, comprises 12 items and is presented in a structured close-ended question format; this section was validated as the Palliative Care Self-Efficacy Scale by Phillips, Salamonson, et al. (2011). The second section is entitled Views concerning death and dying.

Both sections were administered to a mixed sample of nurses (n=405) who had participated in an educational intervention (Phillips et al., 2007). Participants were surveyed at two time points as part of an action research project to enhance the delivery of a palliative approach in the RACF setting. At Time 1, 222 staff completed the instrument; at Time 2, 183 did so. Over half (56%) were nursing assistants, a quarter (25%) were RNs, and 16% were ENs. The authors reported nursing assistants' mean total scores for were lower than in the RN group, and they also scored lower in their capability to answer resident's end-of-life care concerns, although there was no difference in scores on capability to respond to patient's end-of-life symptoms. All groups showed an increase from pre-intervention to post-intervention, approximately 30 months later.

In the validation study of the first section, a factor analysis revealed two subscales reflecting perceived capability to answer end-of-life concerns and perceived capability to respond to symptom management issues. Self-efficacy as described by Phillips, Salamonson and Davidson (2011) is an individual's confidence in and belief about their ability to acquire a specific objective, and so can be increased through the acquisition of knowledge. The validated self-efficacy scale is reported as being able to discriminate between different

educational levels, as well as being sensitive to changes over time (Phillips, Salamonson, et al. 2011). Tool 2.1 has been used in several Australian studies to evaluate the outcomes of educational interventions (Parker & Hughes, 2011; Phillips, Davidson, Ollerton, et al., 2007; Pitman, 2013), and with nursing assistants, RNs and ENs in RACFs (Phillips, Davidson, Ollerton, et al., 2007).

Both components of Tool 2.1 and the validated Palliative Care Self-Efficacy Scale are short, with 10 and 12 items in each part, although it is not reported how long the instrument takes to complete. It is worth noting that the original instruments incorporated into Tool 2.1 and used to evaluate nursing assistants were the Attitudes towards Death Survey and a Survey of Competencies and Concerns in End-of-Life Care for Physician Trainees (Strumpf, 2004; Weissman et al., 1998). The former instrument was designed for all levels of clinical and non-clinical nursing home staff, the latter for medical officers and therefore not specific to nursing assistants' level of education or scope of practice.

2.4.4 The Questionnaire on Palliative Care for Advanced Dementia (qPAD)

The Questionnaire on Palliative Care for Advanced Dementia was developed to measure aged care staff's knowledge, beliefs, perceptions and attitudes about palliative and end-of-life care for people with advanced dementia. It was adapted from the Knowledge Test of Alzheimer's Disease (University of Iowa College of Nursing, 2012) to assess the knowledge of disease aetiology, signs, symptoms, treatment and care of people with Alzheimer's disease. In addition, an attitude scale adapted from the modified version of the End-of-life Care

Decision Questionnaire, used to measure health care professionals' perceptions of and beliefs about end-of-life care processes, (Stoeckle, Doorley, & McArdle, 1998), was included in qPAD's development. The revised questionnaire, Version 2, includes 23 knowledge items and a 12-item attitude scale, taking 20 minutes to complete in all. Additional items were generated by experts: clinical nurse specialists, a psychiatric nurse practitioner, two research nurses, and a behavioural health practitioner (Long et al., 2012). Nursing assistants made up 27% of the sample, which also included social workers, RNs, activity professionals and administration staff. Results were aggregated and reported as a mean score for knowledge items ranging from 0.28 to 0.70. Means for attitudes ranged from 3.060 to 3.929.

The strengths of the instrument are that it evaluates the knowledge and attitudes of RACF staff involved in the care of the person with dementia, the context of residential aged care, and the instrument's brevity. The validity and reliability of the instrument have been established with a factor analysis to determine construct validity and Coefficient Alpha to establish internal consistency.

The weaknesses are that results for nursing assistants were not able to be extrapolated. Neither the two original instruments used to develop qPAD nor the development process included nursing assistants. The Knowledge Test of Alzheimer's Disease is also beyond the level of nursing assistants with entry-level qualifications in Australia (Australian Government Department of Education and Training, 2016a).

2.4.5 An instrument to measure beliefs and attitudes to death, dying, palliative and interdisciplinary care

A fifth instrument, untitled, was developed by Leclerc, Lessard, Bechennec et al., (2014) to measure beliefs and attitudes to death, dying, and palliative and interdisciplinary care. The instrument was based on two questionnaires, one about end-of-life care by Zappa, Hennessy, & Lin (2006) and the other on interdisciplinary clinical practice by Bédard, Poder, & Larivière (2013). It includes 24 items on a 4-point Likert scale. The constructs include interdisciplinary care, care for a patient's relatives, death and end-of-life care, psychological distress, and the feelings of health workers. The instrument was administered to a large sample (n=1, 170) of all categories of aged care staff, including nursing assistants and patient assistants (people who help residents with the activities of daily living).

The response rate was 54% (n=629), with nursing assistants and patient assistants accounting for 75% of the responses. Completion time and psychometric testing of the instrument were not reported. Results, based on average scores of items, showed that attitudes across items were polarised, in agreement, or mixed. A relatively positive attitude towards end-of-life palliative care was found; however, the overall attitudes of the nursing assistants and patient assistants were not as positive as those of other care staff. Leclerc et al. (2014) concluded that more positive attitudes might be related to the educational status of workers, as the data captured a range of clinical and non-clinical staff performing multiple roles. In this respect, the instrument lacks

specificity for the nursing assistant role.

2.4.6 The Comfort Scale

By comparison, the Comfort Scale measures nursing assistants' comfort in providing 12 specific types of end-of-life care. It was developed by Nochomovitz, Prince-Paul, Dolansky et al. (2010) using the Geriatric End-of-Life Nursing Education Consortium Curriculum (Ferrell et al., 2005); additional questions were generated from the literature. A spoken version, an alternative to the paper-based questionnaire, was used to collect data from the sample of 108 nursing assistants. Two response options were provided: 'strongly agree' and 'do not strongly agree'. Associated variables to the study's outcome variable of comfort providing end-of-life care were tested using a multivariable linear regression model. While Nochomovitz et al. reported that 50% of total variance in participants' comfort with end-of-life care was explained by this model (R^2 =0.471), there was limited psychometric analysis provided.

Results showed that the majority of participants expressed strong agreement that they felt comfortable in some aspects of care and observing symptoms; however, only one third strongly agreed that they felt comfortable in their knowledge of end-of-life decisions about care, caring for the deceased, or supporting residents with nausea and vomiting. Only 14% of participants strongly agreed that they felt comfortable talking about death. The implication of this finding is that open and honest discussion about death and dying between residents, staff and families (a key element of a palliative approach) is hindered by a lack of comfort. This finding confirms earlier findings that

nursing assistants lack confidence in knowing what to do or say to dying residents and their families (Beck, Tornquist, Bronstrom, & Edberg, 2012; K. L. Braun & Zir, 2005; Phillips, Davidson, Ollerton, et al,, 2007; Whittaker, George Kernohan, Hasson, Howard, & McLaughlin, 2007). Nochomovitz et al. concluded that comfort levels of nursing assistants in providing end-of-life care equates to the quality of care provided, and that communication is a key element.

Nochomovitz et al. (2010) commented that the strength of the study was the quantitative data on nursing assistants in the context of end-of-life care as measured by the Comfort Scale, as this type of data on nursing assistants was limited at the time of the study. A limitation of the study was the response rate of only 28% of the total sample and a lack of detail on the development and psychometric processes. As well, the authors acknowledged that they could not corroborate participants' self-assessments or their level of knowledge and how they applied it. Importantly, while the study sample involved only nursing assistants, the instrument was based on the End of Life Nursing Education Consortium curriculum, which was developed for RNs.

2.4.7 The Palliative Care Survey

The Palliative Care Survey (PCS) was developed and validated by Thompson et al. (2011) with the aim of measuring both the knowledge and practices of RACF staff. The final sample included 1200 surveys (response rate of 64.6%) from 579 nursing assistants (accounting for 48% of the sample), 180 RNs, 404 LPNs/ENs and 37 social workers. The results showed nursing assistants had significantly lower total practice scores, including bereavement and provider

coordination, compared to the other three groups ($p < 0.05$ for all). Results were based on adjusted means for position and length of time working in nursing homes: nursing assistants 2.64, licensed practical nurses 2.83, RNs 2.84 and social workers 2.98.

A factor analysis confirmed three knowledge subscales related to psychological, physical, and end-of-life knowledge, and four subscales for practice including bereavement, planning/intervention, family communication and provider communication. For family communication, nursing assistants scored lower than the social worker group ($p < 0.05$) and for planning/intervention, nursing assistants scored significantly lower than LPNs and RNs ($p < 0.05$ for both). Nursing assistants also scored lower than all three other groups on knowledge, including total knowledge: 66.7 compared to LPNs (76), RNs (82.3), social workers (80.0), as well as individually on the psychological and end-of-life symptoms. They did however, score higher on the physical items compared to the social worker group. Thompson et al. commented that knowledge about physical symptoms was uniformly high across all groups, but low scores were obtained by all groups for the end-of-life items in the knowledge component. The stability of the instrument over time was not demonstrated in the initial study.

A limitation of this instrument, acknowledged by the authors, is the lack of specificity for nursing assistants, as items cover a range of knowledge and practices of aged care staff.

Table 2

Summary of instruments

Instrument	**Palliative Care Quiz for Nurses (PCQN)**	**Bonn Palliative Care Knowledge Test (BPW)**	**Tool 2.1**	**Questionnaire on Palliative Care for Advanced Dementia (qPAD) (revised and expanded to Qpad2)**	**Questionnaire to measure beliefs, values and attitudes towards death, dying, palliative and interdisciplinary care**	**The Comfort Scale**	**The Palliative Care Survey**
Development sample	RNs =196, tertiary-level nursing students =200	Phase 1 = 36 aged care nurses (not specified), trained in palliative care; phase 2 = 23 nursing experts in palliative care	Tool 2.1: Unknown Palliative Care Self-Efficacy Scale: Nursing assistants =111, RNs=62, ENs =36	Nursing assistants =24, ENs =16, RNs =2, caregivers = 17, others =16	Patient assistants =329, nursing assistants =144, RNs=69, others =88	Nursing assistants =108	Phases 1,2: Nursing assistants = 1784, ENs =548, RNs = 420, others = 576
Time to complete	20 minutes	10 minutes	Not reported	qPAD2 20 mins	10-15 minutes	Not reported	20-30 mins
Development process	Item generation by experts (palliative care	Existing measures: 1. Palliative	Use of existing measures by Strumpf (2004)	USA, 2006 (adapted from the Knowledge	Adapted questions from two questionnaires:	Qualitative data on nursing home care (first author) and	

	nurses)	Care Quiz for Nurses (PCQN) (Ross et al., 1996) and 2. Palliative Care Knowledge Test (Nakazawa et al., 2009); additional items generated by experts; Self-efficacy: Test Instrument for Palliative Care (Adriaansen & Achterberg, 2004) items modified	and Weissman and colleagues (1998)	Test of Alzheimer's Disease (KAT) (University of Iowa Nursing, 2012) and the EOLCDQ11 (Stoeckle, Doorley & McArdle, 1998) plus additional items generated by experts (n=4)	Zapka et al., 2008 and IPC65, Bedard et al., 2013).	literature review
Validity: construct	–	–	Validated in part (12 items) by Phillips, Salamonson, and Davidson (2011)	Principal components factor analysis (knowledge=3 factors using an	–	Principal components exploratory factor analysis with varimax rotation supported four hypothesised

			two factors, eigenvalues >1.0 Perceived capability to answer patients EOL concerns (54.6% of total variance) Perceived capability to respond to patients EOL symptoms (10.7% of total variance)	oblique rotation model, accounting for 67% total variance. Attitude scale items analysed using an orthogonal rotation =3 factors 68% variance)		subconstructs 1. Bereavement 2. Planning/intervention 3. Family communication 4. Provider communication Palliative Care Knowledge, three subconstructs 1. psychological, 2. physical, and 3. EOL factors
Face	Advisory committee	–	–	–	16 participants – process not discussed	Part of process outlined below
Content	Item review by advisory committee (n= –) using Likert scale 1-5 for correctness of response, clarity and relevance Random sample of individuals	Knowledge item review by five experts in palliative care – process not detailed; Self-efficacy items reviewed by	–	Knowledge items reviewed by experts (n=4) following pilot; process not identified	–	16 participants completed survey and participated in a face-to-face discussion with an interviewer. Items revised or deleted based on staff comments.

	involved in palliative care education (n=166) to rate knowledge dimensions on Likert scale 1-5	five experts on a 5-point Likert scale Total instrument items with five experts using the think-aloud method (4-reponse options)				
Criterion	–	–	–	–	–	–
1.Concurrent	–	–	Scores of total scale and subscale at two time points time 1 and time 2 (24-30 months) non-paired sample – Comparison of RNs and enrolled/nursing assistants, and post education, using Mann-Whitney U test	–	–	–
2.Predictive	–	–		–	–	–
3.Convergent	Analysis of variance between nurses and students using the Scheffé's procedure	Mann-Whitney U test was used to compare item differences between the sample group aged care staff (n=36) and expert		–	–	Analysis of variance between licensed nurses and unlicensed staff; item means from 1.84 to 3.63 (range 1-4) on Palliative Care Practice subconstructs; for Knowledge, mean proportion correct
4.Discriminant						

		group of palliative care nurse trainers (n=23)	(p<0.001) for group and education			scores range 0.27-0.99 (range 0.00-1.00)
RELIABILITY 1. Internal consistency	Kuder-Richardson (KR-20) 0.78	Cronbach's alpha 0.71 for knowledge items; 0.86 for self-efficacy items. Mann Whitney U test (p=<0.002 for knowledge; p=<0.003 for self-efficacy)	Cronbach's alpha 0.92 (subscales 0.87-0.91)	Cronbach's alpha 0.81/0.83 for knowledge and attitude respectively	–	Cronbach's alpha 0.75/0.81 for overall Practice and Knowledge constructs

2.Test-retest	The correlation coefficient between time 1 and time 2 0.56 (3-week interval); no statistical significance in scores (t=0.19, df =27, p=0.99)	–	–	–	–

2.5 **Discussion**

Of all seven instruments available to evaluate the knowledge, skills and attitudes of nursing assistants and a palliative approach, only the Comfort Scale was designed to evaluate the degree to which nursing assistants perceive themselves as possessing the necessary training, skills and knowledge to feel comfortable about providing end-of-life care (Nochomovitz et al., 2010), but it was not validated for nursing assistants. A summary of the strengths and limitations of existing instruments are shown in Table 3.

The PCQN is the most widely used knowledge test for nursing assistants, and has also been used to inform the development of a further instrument in this review (Pfister, Muller, Muller, Core, et al., 2011). While it is an efficient tool to administer its suitability is questionable, given its development process and the lack of specificity for nursing assistants' level of education and scope of practice. As well, its application to older people with palliative care needs in RACFs is limited. Studies reporting on the knowledge of nursing assistants in a palliative approach using the PCQN tend to overlook the validity and reliability of the instrument for this population and the broader context of a palliative approach.

Table 3

Strengths and limitations of existing instruments

Instrument	Strengths	Limitations
Palliative Care Quiz for Nurses (PCQN) (Ross, McDonald & McGuinness, 1996)	Easy to administer, time-efficient, sensitive to change pre/post test, discrimination between groups	Designed for RNs—not developed for population or RACF setting Biomedical/pharmacological knowledge relative to RNs. Health literacy
Bonn Palliative Care Knowledge Test (BPW) (Pfister, Muller, Muller, Core, Rai & Radbruch, 2011)	Easy to administer, time-efficient, sensitive to change pre/post test, discrimination between groups	Existing measures to test nurses and physicians—not developed for population or RACF setting Biomedical/pharmacological knowledge relative to RNs Health literacy
Tool 2.1 (Eager**,** Senior, Fildes, Quinsey, Owen, Yeatman & Posner, 2003)	Brevity, simplicity, sensitivity to change, discrimination between groups	Existing measures for nursing home staff and medical officers—not developed for population or RACF setting Medical knowledge required

Questionnaire on Palliative Care for Advanced Dementia (qPAD) (revised and expanded to Qpad2) (Long, Sowell, Hess & Alonzo, 2012)	Able to evaluate staff knowledge of advanced dementia, not covered in existing instruments	Specific to advanced dementia care; adapted from existing measures Not developed for population of nursing assistants
Questionnaire to measure beliefs, values and attitudes towards death, dying, palliative and interdisciplinary care (Leclerc, Lessard, Bechennec, Le Gal, Benoit, & Bellerose, 2014)	Covers broad spectrum of elements of a palliative approach for training purposes	Designed for all levels of RACF staff: managers to volunteers Not developed for population
The Comfort Scale (Nochomovitz, Prince-Paul, Dolansky, Singer, DeGolia, & Frank, 2010)	Specific to the role of nursing assistant. May be available as a spoken questionnaire	Based on End of Life Nursing Education Consortium curriculum for RNs; self-report measure; no validation study
The Palliative Care Survey (Thompson, Bott, Boyle, Gajewski & Tilden 2011)	Focus on care practices and behaviours, content, construct validity discrimination between groups	Length of survey (51 items) Complicated scoring based on weighted scores Covers a range of practices and levels of knowledge—not tailored for population

Other knowledge instruments used with nursing assistants in the RACF setting include the Palliative Care Survey (Thompson et al., 2011) and the German Bonn Palliative Care Knowledge Test (Pfister, Muller, Muller, Core, et al., 2011). Thompson et al. (2011) reported on a study to evaluate the psychometric properties of the Palliative Care Survey (PCS) for use in RACFs in the United States, used subsequently by Unroe et al. (2015). Nursing assistants were included in the face validation process (number unknown) and in the pre-testing (n=360) and larger scale field testing (1,424) of the instrument. However, the PCS encompasses a range of practices and levels of knowledge across RACF staff involved in various processes, so that gaps in nursing assistants' knowledge related to their direct care role are not identified.

Nursing assistants' low levels of knowledge of palliative care has been recorded internationally. Two studies by Pfister, Muller, Muller et al. (2011) and Kada, Janig, Pinter, Cernic and Likar (2017) used the Bonn Palliative Care Knowledge Test (Pfister, Muller, Muller, Core, et al., 2011). Pfister and colleagues (2011), in their research with nursing employees in Germany, measured knowledge using this test. Across all four groups of nursing participants (assistant nurses for the elderly (n=40), nurses for the elderly (n=36), general nurses (n=18) and 'others' (n=14), only 52.8% correct responses were recorded. They also found a negative correlation for self-efficacy with age and working experience in the nursing assistant group. This finding was in contrast to knowledge that correlated positively with work experience. The authors concluded that younger, inexperienced

caregivers may underestimate the complexity of providing high-quality palliative care and of developing supportive relationships with older people, while these facets of care are better understood by older, more experienced caregivers who have higher quality expectations about palliative care (Pfister, Muller, Muller, Core, et al., 2011).

Similarly, using the BPW test described above, Kada, Janig, Pinter, Cernic and Likar (2017) measured the knowledge and self-efficacy of nursing staff (n=330) in a province in Austria. Little more than half the knowledge items were correctly answered by participants, and RNs scored higher than nursing assistants for both knowledge and self-efficacy. The authors reiterated the recommendations for interventions aimed at increasing nurses' knowledge as a means to improving palliation in nursing home residents (Kada et al., 2017).

While it is expected that RNs will perform better than nursing assistants based on education, the design and development of the instrument needs to be examined to determine if it is relevant for nursing assistants' scope of practice. Examination of the knowledge items (e.g. ,the provision of anti-depressants in pain treatment), and the self-efficacy items (e.g., counselling a patient about how nausea can be alleviated), do not correspond with nursing assistants' level of education or scope of practice , given their emphasis on knowledge of medications and physiological processes.

The majority of reviewed instruments have been adapted from existing measures and developed for RNs and a range of other health care

personnel. Tool 2.1 (Eager et al., 2003), the Bonn Palliative Care Knowledge Test (Pfister, Muller, Muller, Kern, et al., 2011), and the (untitled) questionnaire to measure beliefs, values and attitudes towards death, dying, palliative and interdisciplinary care (Leclerc et al., 2014) have been adapted from previous measures originally intended for medical students, residents and interns (Weissman et al., 1998), nurses and general physicians (Nakazawa et al., 2009; Pesut et al., 2015; Pfister, Muller, Muller, Core, et al., 2011; Ross et al., 1996; Thompson et al., 2011) or interdisciplinary health professionals caring for patients with advanced heart failure (Zappa et al., 2006). While all instruments have been used in the residential aged care setting, only the Comfort Scale incorporates content exclusively focused on the role of the nursing assistant in the RACF setting. While specific, the sample for this study was the smallest of all development samples discussed in this review and is not able to be generalised across this workforce.

By comparison, Tool 2.1 was broadly compiled to evaluate palliative care projects in various settings (Eager et al., 2003). It has subsequently been used by Parker, Clifton and Tuckett (2011) Phillips, Davidson, Ollerton, et al., (2007) and Pitman (2013) in Australian studies to evaluate the outcomes of educational interventions.

Parker et al. (2011), who reported on the Comprehensive Evidence-Based Palliative Approach in Residential Aged Care project in Australia, used Tool 2.1 Palliative Care Providers for data collection. The project, which

produced the Palliative Approach Toolkit (University of Queensland/Blue Care Research & Practice Development Centre, 2012), involved more nursing assistants than nurses, drawn from nine RACFs across four Australian States and attending education sessions on core topics in a palliative approach, case conferencing, terminal care, and end-of-life care pathways. It used a pre- and post-test survey design and found an overall improvement in staff knowledge and skills in providing a palliative approach. Yet the data on nursing assistants' outcomes suggests only modest improvements: only 34% indicated they felt confident to react independently to reports of pain from the resident; only 36% strongly disagreed with the statement that a resident should experience discomfort before their next dose of analgesia; and only 44% (compared with 70% of RNs) strongly agreed that terminally ill residents should receive pain medication as needed. Post-intervention data indicated that 83% of nursing assistants (88% pre-intervention) indicated that control of pain decreased in importance as a problem they faced when caring for a dying resident, indicating this was still a problem area for the majority. On their post-intervention views about death and dying, nursing assistants exhibited a 10% increase in two of the ten items: the use of feeding tubes to prevent starvation at the end of life, and confidence in dealing with a dying resident.

Baseline data on staff did not, however, indicate a high level of competence in delivering a palliative approach. The post-survey data suggested only modest improvements for nursing assistants. The data collected from the chart audits that reported improved outcomes in the use of pain

assessment tools also documented evidence of pharmacological and non-pharmacological treatments and oral care, although it was unclear which levels of staff were responsible for each. Possible reasons why competence for nursing assistants improved only modestly include extrinsic variables such as workload, staffing and limited resources, which Andrews, McInerney and Robinson (2009, p. S67) identify as constraints in an evidence-based agenda. Another possible reason is the sensitivity of the instrument used to evaluate this population, which applies similarly to the partially validated component, the Palliative Care Self-Efficacy Scale (Phillips, Salamonson, et al., 2011).

Tool 2.1 Palliative Care Providers (Eager et al., 2003), the Palliative Care Quiz for Nursing (Ross et al., 1996) and the End of Life Nursing Education Consortium test (modified from a version that was validated in Japan by Takenouchi, Miyashita, Tamura, Kizawa, & Kosugi, 2011) were used in an amalgamated form by Pitman (2013), who evaluated the effectiveness of a self-directed learning package for increasing palliative care knowledge and confidence for Australian rural aged care workers in three RACFs (n=33). The research sample included nursing assistants (n=29) who made up 88% of the sample and 83% of the total study population. It is not clear which items from each test were used, but the aggregated results showed an improvement in knowledge by a mean of 1.3 points, and in confidence by a mean of 0.9 points. A second post-test six months later reported a further increase in knowledge, but confidence declined after six months. It is not possible to extrapolate results for the different groups from the overall

small sample. Limitations include not knowing the specific test items and, as noted by Pitman, not being able to tell if knowledge improved because of intervening education during the six-month period, or what effect the improved knowledge had on work practice and resident outcomes.

The majority of instruments discussed in this review are limited in their relevance to nursing assistants' level of education and scope of practice because of the higher level of biomedical and pharmacological knowledge and overall health literacy of the sample for whom they were originally developed. These limitations are underscored by the overall low results of nursing assistants. An additional problem compounding educational status is the comprehensibility of existing instruments for the majority of aged care employees, who are an increasingly culturally and linguistically diverse workforce (Mavromaras et al., 2017; Negin, Rozea, Cloyd, & Martiniuk, 2013; Ronaldson et al., 2008).

In terms of practicality and transferability, the Bonn Palliative Care Knowledge Test (Pfister, Markett, et al., 2013), the questionnaire to measure beliefs, values and attitudes towards death, dying, palliative and interdisciplinary care (Leclerc et al., 2014) and the Palliative Care Nursing Self-Competence (PCSNC) scale were originally administered in languages other than English (German and French), limiting their transferability to an English-speaking workforce without translation and re-validation of the instrument in English.

The Comfort Scale (Nochomovitz et al., 2010) was administered as an audio

questionnaire, which, while providing an advantage for participants for whom understanding written English may be difficult, may create a different set of problems related to transcribing the responses that may be an obstacle to the utility of such a mode of evaluation. The qPAD (Long et al., 2012), with its specificity for evaluating knowledge of advanced dementia, does not evaluate more generalised knowledge or skills in a palliative approach when caring for cognitively intact older people who may wish to discuss their existential concerns at end of life (Waskiewich, Funk, & Stajduhar, 2012).

Studies using existing instruments have consistently shown nursing assistants to have a low knowledge of palliative care when compared with RNs/ENs: but, as is clear by now, none of the instruments has been developed to assess the spectrum of knowledge—from poor to excellent—of this group. Many have been adapted from existing measures used to assess a range of health professionals and raise key methodological issues. Ugalde, Krishnasamy and Schofield (2011), arguing that statistical processes for reliability and validity do not guarantee relevance when applied to populations other than those for whom they were intended, recommend tailoring instruments to a specific target group. While literature is important to augment theory, qualitative data collection to capture the attitudes of the target group as well as to delineate relevant issues is acknowledged as a limitation in the development of one of the instruments included in this review (Leclerc et al., 2014). As has been stated throughout this review, nursing assistants' level of education and

scope of practice is different to the required core competencies of RNs/ENs and other health care professionals (Australian Government Department of Health, 2014).

Many of the instruments in this review have evaluated knowledge of a palliative approach, but only three have evaluated skills and attitudes as key attributes in palliative care provision. Of these, Tool 2.1 examines the attitudes of palliative care providers towards palliative care. This instrument has been rebranded as a self-efficacy scale identifying two components: responding to end-of-life concerns and responding to symptoms. While these are issues that concern nursing assistants, many of the items in the tool focus on symptom management and physiological processes, reflecting the original target group of trainee medical officers (Weissman et al., 1998) and having little relevance to the experience of nursing assistants. For these reasons, a tailored instrument that is relevant, valid and reliable for this target group is warranted.

Of the other two instruments developed to evaluate beliefs, perceptions and attitudes, the Questionnaire on Palliative Care for Advanced Dementia (qPAD) focused on one specific diagnostic group (Leclerc et al., 2014) and the untitled instrument to measure beliefs and attitudes to death, dying, palliative and interdisciplinary care encompassed all levels of RACF staff (Long et al., 2012). The limitations of the former include not evaluating aged care staff's beliefs, perceptions and attitudes concerning those people with diagnoses other than dementia and the latter lacks focus on the direct

care that nursing assistants provide. Furthermore, neither instrument capture how nursing assistants feel when providing care with a palliative approach, to the majority of RACF residents who have physical, emotional, psychological and spiritual needs and who will die in the RACF setting. This information can potentially serve as a guide to the types of support services for staff to manage the stressors of the work environment.

Despite their limitations, all instruments discussed here have contributed to the evaluation of the current palliative care competency of nursing assistants in RACFs, where previously a lack of RACF-specific instrumentation for evaluation purposes was identified (Thompson et al., 2011). The lack of measurement for generalist providers of palliative care overall has been corroborated by Frey, Gott, Banfield and Cambell (2011) in a systematic review, who concluded that no single validated instrument existed to measure the perceived competence in palliative care management or the delivery of palliative care by generalists or primary care providers. Of the 19 studies in their review, only three examined perceived competence in nurses, and only one of these included nursing assistants (Dryden & Addicott, 2009): an evaluation of a pilot study day for health care assistants and social care officers in the United Kingdom, which aimed to assess the knowledge of and confidence in palliative care provision of the participants in a self-administered questionnaire covering six topics from the Marie Curie Cancer Care Programme: pain, breathlessness, depression, nausea and end-of-life care. A 10-point scale ranging from 1 - very little to 10 - extremely knowledgeable, and a 10-point

scale for confidence from 1 - not at all confident to 10 - extremely confident, was used for evaluation purposes. Validation was not established for the questionnaire which was also specific to a cancer focus, and applied in a setting where neither the training nor the instrument was specific to residential aged care.

The other instruments identified in the systematic review by Frey, Gott, Banfield et al. (2011) were developed for a range of health care professionals, the majority for self-administration. It can be argued that instruments used to measure the knowledge and confidence of health professionals and non-professionals require further scrutiny, especially given that the emphasis on physical symptom management in many of them (Frey, Gott, & Neil, 2013) is beyond non-professionals' level of education and scope of practice.

This literature review highlights the lack of a tailored instrument for nursing assistants' level of education and scope of practice. As would be expected, nursing assistants generally score lower than all other groups across the various domains measured by existing instruments. There is variability in nursing assistants' knowledge, skills and attitudes within a palliative approach, and low conceptual knowledge of palliative care as measured by existing instruments. Given the differences in education between nursing assistants and tertiary-educated nurses, a valid and reliable measurement tool suitable for nursing assistants' scope of practice is warranted. Such an instrument would identify knowledge and skills

deficits relevant to nursing assistants' scope of practice and detect detractors from positive attitudes required for high-quality palliative care in RACFs.

2.6 Gaps in the research

One instrument only—the Comfort Scale—was developed for nursing assistants within the context of residential aged care (Nochomovitz et al., 2010), although this was based on an existing curriculum for RNs (Ferrell et al., 2005). No instrument has been developed or validated specifically for nursing assistants' level of education or scope of practice within RACFs, nor to measure differences within the population of nursing assistants.

Tailoring an instrument specifically to the educational level, health literacy and care processes in which nursing assistants are involved requires adhering to psychometric processes to ensure a sound instrument for this population. A valid and reliable instrument suitable for nursing assistants' level of education and scope of practice is necessary to determine how prepared nursing assistants are to provide care with a palliative approach. The lack of such an instrument impacts negatively on the ability to ascertain the training and development needs of this level of aged care worker in RACFs, the evaluation of care processes, and the outcomes of interventions in a palliative approach.

2.7 Chapter summary

This chapter has examined the instruments which have been used by the

RACF sector to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach, critically examined the development processes involved, and evaluated the strengths and limitations of these instruments for nursing assistants' level of education and scope of practice. The final section highlights the research gap, demonstrating that no present instrument has the capacity, reliability or validity to measure nursing assistants' knowledge, skills and attitudes within a palliative approach.

The following chapter presents the methodology used to develop such an instrument, followed by the conceptual framework used to inform item generation. The ethical considerations of the study are also discussed.

Chapter 3 Methodology and Conceptual Framework

3.1 Overview

This chapter is divided into two sections. The first discusses the methodology used to conduct the study. The purpose, specific hypotheses and research design are presented. The rationale for the selection of this research design and its application in this study is discussed, followed by an overview of each of the study's four sequential phases, which are discussed in detail in following chapters. In the second section, the conceptual framework for a palliative approach to guide the development of a new instrument for nursing assistants is presented. The chapter concludes with the ethical considerations applicable to this study and how these are managed, followed by a summary of the chapter.

3.2 Methodology

3.2.1 Study purpose

Following the literature review and critical examination of existing instruments, the third purpose of this study is the design, development and validation of an instrument to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach.

3.2.2 Study hypotheses

There are five specific hypotheses applicable to this study. It is hypothesised that an instrument designed specifically for nursing

assistants' level of education and scope of practice

I. will perform better than the Palliative Care Quiz for Nursing (PCQN) (Ross et al., 1996) in discriminating knowledge of a palliative approach between groups of nursing assistants;
II. will demonstrate that experience measured as length of time in the nursing assistants' role will be a better predictor than education in discriminating knowledge of a palliative approach between groups of nursing assistants;
III. will detect differences between groups of nursing assistants for knowledge of a palliative approach based on experience in the role;
IV. will detect differences between groups of nursing assistants in skills for a palliative approach based on experience in the role;
V. will detect differences between groups of nursing assistants for attitudes towards a palliative approach based on experience in the role.

3.3 **Hypothesis testing**

The relevance of these hypotheses to the development of the instrument is, first, to confirm that the instrument can be used to evaluate differences between groups with varying levels of experience and education; and, second, to provide insight into the effectiveness of current educational processes. While there is little research to guide predictions about the range of knowledge, skills and attitudes in a palliative approach between groups of nursing assistants based on experience, Pfister, Markett, et al.

(2013, p. 795) found that general knowledge of palliative care correlated with nursing assistants' work. However, they also found a negative correlation between self-efficacy, defined as 'one's own ability to complete tasks and define goals', and both age and experience. They concluded that older and more experienced nursing assistants were less confident than their younger and less experienced co-workers, who may overestimate the acquisition of palliative care skills. Possible reasons for this finding are that as nursing assistants are enculturated into residential aged care, their exposure to the setting and to residents requiring a palliative approach increases their knowledge and understanding of palliative care needs; however, this improved knowledge does not translate into improved skills and confidence, especially when there are few professional development opportunities by which to implement their knowledge. As well, skill acquisition, a component of competency development, requires the integration of many attributes, including self -awareness, managing uncertainty, and scientific and humanistic judgement (Perieira, 2006). The relevant literature review available to this study does not make clear to what extent nursing assistants are supported to develop skills in a palliative approach, although without specific palliative care training, nursing assistants undoubtedly experience difficulties in skill acquisition and developing a capacity for evidence-based practice.

Evaluation of nursing assistants' attitudes as an aspect of competence in a palliative approach is not well represented in the literature when compared to the evaluation of knowledge. Only two of the seven instruments

reviewed evaluate views and attitudes about palliative care (Eager et al., 2003; Leclerc et al., 2014); yet positive attitudes towards palliative care are not developed by knowledge alone. A study by Cohen, O'Connor and Blackmore (2002) found that while experience working in palliative care is associated with positive attitudes, the beliefs and emotions of staff need also to be taken into consideration. Positive attitudes are a core component of palliative care competency, such that care providers can appreciate a range of human responses, accept quality of life choices and demonstrate respect at all stages of the illness trajectory (Community Services and Health Industry Skills Council, 2015; Australian Government Department of Health, 2014). Attitudes, along with knowledge and skills, warrant examination in nursing assistants who experience continuous interactions with residents and families.

3.4 **Study design**

A mixed methods design was selected for the development of the new instrument. Mixed methods research has been described as an intuitive and practical way to understand complex problems in health and social care by drawing on the strengths of both the traditional quantitative and qualitative methodologies (Fetters, Curry, & Creswell, 2013; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). One of the rationales for using a mixed methods approach is that qualitative inquiry strengthens the development of quantitative instruments (O'Cathain, Murphy, & Nicholl, 2010; Onwuegbuzie, Bustamante, & Nelson, 2010). Specifically, this approach

enhances the description and understanding of the construct and contributes to instrument fidelity (R. Johnson, Onwuegbuzie, & Turner, 2007).

This study was conducted using a four-phase sequential mixed methods design. A sequential mixed methods design is typically used to develop quantitative instruments, whereby data is collected in the first phase to inform subsequent phases (Östlund et al., 2011). The four phases used to develop the instrument consisted of Phase 1: Item generation; Phase 2: Instrument development; Phase 3: Pilot test; Phase 4: Instrument testing. Generally, phases conducted in sequential order provide a set of analytical approaches to confirm and validate findings generated from the preceding phase (Onwuegbuzie et al., 2010). In this study, qualitative data collected in Phase 1 and 2 was used to inform the quantitative Phases 3 and 4.

As well as being described as a distinct methodology, a mixed methods approach also provides a framework on which to develop the instrument, starting with conceptualising the construct of interest (Onwuegbuzie et al., 2010). In Phase 1, data was collected on nursing assistants' perspectives of the concept of a palliative approach. This qualitative component added depth and breadth to the research by reflecting the subjective, real-life contextual understandings and cultural influences of participants (DeVon et al., 2007; Lasch et al., 2010; Luyt, 2012; Ugalde, 2009). Analysis of this data using a deductive, thematic approach based on the conceptual framework and a priori themes in the literature informed the development of items.

Qualitative data was also a component in Phase 2, in which experts were asked to validate the content of items and provide feedback. The feedback was used in decision-making to both modify items and generate additional items. The inclusion of qualitative data contributes to measurement validation, defined as the extent to which an instrument measures what it intends to measure, and ensures that the instrument is a valid indicator of the construct, as well as guaranteeing the relevance of final items to the target population of nursing assistants (DeVellis, 2012; Luyt, 2012; Polit & Beck, 2017).

While the qualitative data in Phases 1 and 2 provided unstructured data using words and phrases, subsequent data collection in Phases 3 and 4 using the survey method generated data requiring quantification. Statistical analysis techniques were used to analyse the quantitative numerical data as they provided a means to validate items objectively (Collins & O'Cathain, 2009). The validation processes in this study provided the evidence that the instrument will deliver accurate information and that subsequent research findings can be guaranteed (DeVon et al., 2007; Polit & Beck, 2017).

The incorporation of both qualitative and quantitative methods to enhance research findings requires the flexibility offered by a mixed methods design, which is a defining feature of this methodology (R. Johnson et al., 2007; Onwuegbuzie et al., 2010). The mixed methods elements of this study are the qualitative data collection and thematic analysis used for item generation in Phase 1; and the survey method and quantitative, deductive

and statistical analyses used to endorse items for the final instrument in Phases 2, 3 and 4. Underlying this mixed method research are two paradigms: that of naturalistic enquiry, with a focus on the authenticity, credibility and trustworthiness required of qualitative studies; and that of a positivist scientific paradigm, with its emphasis on validity and reliability (Creswell, Klassen, Plano Clark, & Clegg Smith, 2010; Greene, 2008; R. Johnson et al., 2007). Both are applicable to this study.

Figure 1 presents a visual summary of the four sequential phases of the study. The phases are discussed in detail, one in each of the next four chapters. The visual summary is followed by a discussion of the conceptual framework used to inform the development of the instrument, and specifically the generation of items in Phase 1.

Phases	→	Procedures	→	Products
Phase 1		QUALITATIVE		Transcribed texts
Item Generation	→	Semi-structured interviews	→	Themes – categories – items
		Thematic/deductive analysis		
		Generation of items		
Phase 2		QUANTITATIVE/QUALITATIVE		Item pool
Instrument Development	→	Survey method	→	Draft instrument(s) – PANA
		Descriptive statistics, Content Validity Index		Dichotomous/scaled variables
Phase 3		QUANTITATIVE/QUALITATIVE		Draft instrument(s) – PANA
Pilot Testing	→	Survey method	→	Mean scores, standard deviations, confidence
		Descriptive statistics, mean scores, thematic		intervals, summary tables
		analysis		
Phase 4		QUANTITATIVE		Individual item properties, factor structure
Instrument Testing	→	Survey method	→	Mean scores, standard deviation, factor
		Individual item analysis, Kendall's Tau		structure, Cronbach's Alpha, Pearson's
		Correlation, analysis of variance, factor		product moment correlation coefficient,
		analysis, reliability testing		Final instrument: Three questionnaires

Figure 1 Overview of study phases, procedures and products

Note: Adapted from Creswell (2009) Ch. 22.

3.5 **A conceptual framework**

Key aspects of instrument development are the conceptualisation of the construct of interest, the research philosophy and world view, and the philosophy of the relevant discipline (Onwuegbuzie et al., 2010). Ontological, epistemological and philosophical foundations support the conceptualisation of the construct of a palliative approach, incorporating both its theoretical and practical elements. In this research, these foundational points of reference view a palliative approach as a medical and nursing speciality within the biomedical model, and as a construct of contemporary developed health care systems and institutions. Outside contemporary health care, this construct does not exist. In fact, the 'novelty' of a palliative approach as a concept is described as limiting the literature that can be used to develop practice in settings such as residential aged care, because of the association of palliative care with medical specialisation (Reimer-Kirkham, Hartrick Doane, et al., 2015, p. 197). In comparison, dying and death, as universal experiences, are historically located within the social context of people's lives (Rosenberg, 2011). Understanding a palliative approach is important in framing this research because of its particular relevance to the setting of residential aged care, and the population of nursing assistants providing care to the older person approaching the end of life.

Determining what needs to be included in a new instrument requires a conceptual framework, as the substantive theoretical aspects related to a palliative approach need to be understood before the construct can be

operationalised into items (DeVellis, 2012). On a practical level, the instrument needs to capture the essential knowledge, skills and attitudes required by nursing assistants to apply the key philosophy and principles of care within a palliative approach.

3.5.1 A palliative approach

A 'palliative approach' has been adopted as the terminology to conceptualise the provision of palliative care to people with a range of chronic, life-limiting illnesses, by health professionals who are not specialists in palliative care (Cameron-Taylor, 2012; Kristjanson, Walton, and Toye, 2005; Reimer-Kirkham, Sawatzky, Roberts, Cochrane, & Stajduhar, 2016; Sawatzky et al., 2016; Shadd et al., 2013). The definition of palliative care endorsed by the World Health Organisation states that palliative care is:

> an approach that improves the quality of life of individuals and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Sepulveda, Marlin, Yoshida, & Ullrich, 2002, p. 94.)

Access to palliative care is based on need irrespective of diagnosis, age, cultural background or location (Palliative Care Australia, 2018). With the focus on need rather than diagnosis, a palliative approach is viewed as a valid option for people with advancing, chronic, life-limiting illness, including older people with palliative care needs in residential aged care facilities (Cronfalk et al., 2015; Kristjanson et al., 2005). As well, the recognition of patients with palliative care

needs from medical specialties other than oncology are being articulated across the world (Barrett, 2016; Reimer-Kirkham, Sawatzky, et al., 2016; Siouta et al., 2016; Wong et al., 2016).

A palliative approach is ideally applied early in the disease trajectory, to help manage symptoms as they arise and because many people with palliative care needs, who are not dying of cancer, experience a trajectory of frailty and gradual decline in function (Australian Government Department of Health and Ageing, 2006). This is especially the case for older people, and within the context of advancing dementia, which is prevalent in RACFs (Australian Institute of Health and Welfare, 2016).

3.5.2 *Guidelines for a palliative approach in residential aged care*

In this study, what constitutes a palliative approach as applied in RACFs has been articulated in national guidelines, based on evidence from the disciplines of medicine and nursing and the specialties of palliative care, geriatrics and gerontology (Australian Government Department of Health, 2006). The first national evidence-based *Guidelines for a palliative approach in residential aged care* were developed in Australia in 2004 and enhanced in 2006 (Australian Government Department of Health, 2006), developed by the Australian Palliative Residential Aged Care project team to provide support and guidance for the delivery of a palliative approach in the 3,000 residential aged care facilities across Australia at that time.

For older people in RACFs, a palliative approach aims to improve quality of life, to maintain function where possible, and to preserve dignity and comfort

during the transition to end of life. The *Guidelines* focus on the palliative care needs of older people in this setting, synthesising geriatric, gerontological and palliative care expertise to address the presence of pain and distressing symptoms, the presence of dementia, and families' needs related to end-of-life care (Hegarty & Currow, 2006; Kristjanson et al., 2005). The intent of the *Guidelines* is to provide guidance and support to all those caring for people with a life-limiting illness or condition in residential aged care facilities. For this reason, they provide the conceptual framework for the instrument developed here.

3.5.2.1 Developing the guidelines

The development of the guidelines involved a broad consultation process that included both palliative and aged care sectors, and consultation with other key stakeholders, in focus group discussions and feedback sessions. The feedback loops during the development process included a useability and feasibility assessment by team members (n=36) from three aged care facilities. One high-care facility, one low-care facility and one remote and regional facility were selected for this process to ensure representation from all tiers of the sector (Australian Government Department of Health, 2006). This same process was applied in the present study to incorporate wide consultation during the instrument's development. In Phases 1, 3 and 4, this included representation of profit and not-for-profit facilities offering high and low-level care places, and the participation of four groups of experts to validate content in Phase 2.

For the conceptual framework, the seventy-nine guidelines were used as

criteria to inform content coverage for the new instrument. These were represented by 12 overarching subject headings and 27 subheadings (see Table 4). From these subject headings, six are applicable to the level of education and scope of practice of nursing assistants:

1. A Palliative Approach
2. Physical Symptoms – Assessment and Management
3. Family Support
4. Social Support
5. Cultural Issues
6. End of life (Terminal Care)

These headings were confirmed for their applicability to nursing assistants' level of education and scope of practice based on their alignment with the essential knowledge and skills outlined in the educational unit *Deliver care services with a palliative approach* in the Certificates in Aged Care (Community Services and Health Industry Skills Council, 2015).

Table 4
Guidelines for a Palliative Approach in Residential Aged Care

Content	Specific content	Guideline
1. A Palliative Approach	When a palliative approach should be implemented	1-2
	Where a palliative approach be provided	3
	Who provides a palliative approach	4
	Dignity and quality of life	5-6
	Advance care planning	7-9
	Advanced dementia	10-14
2. Physical Symptoms: Assessment and Management	Symptom assessment	15-17
	Pain management	18-19
	Fatigue	20
	Nutrition and hydration	21-26
	Cachexia	27-28
	Dysphagia	29-30
	Mouth care	31-33
	Skin integrity	34-35
	Bowel care	36-39
	Dyspnoea	40-43
	Complementary therapies	44-49
3. Psychological Support	Depression	50-51
	Anxiety	52
	Delirium	53
	Dementia	54
	Psychological distress	55
4. Family Support		56-59
5. Social Support – Intimacy and Sexuality	Social support	60
	Intimacy	61
	Sexuality	62
6. Aboriginal and Torres Strait Islander Issues		63-65
7. Cultural Issues		66-67
8. Spiritual Support		68-70
9. Volunteer Support		71-73
10. End of Life (Terminal Care)		74-75
11. Bereavement Support		76-78
12. Management's Role in Implementing a Palliative Approach		79

3.5.3 Deliver care services using a palliative approach

While the *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006) provide the conceptual framework for content coverage of the new instrument, the knowledge and skills that are relevant for nursing assistants in care processes within a palliative approach need to be distinguished from the clinical aspects of care provided by RNs and other providers of care.

As nursing assistants receive basic education and training at certificate level but may not receive any professional development education in palliative care (Australian Government Department of Employment, 2016; Frey, Boyd, et al., 2016; King et al., 2012), *Deliver care services using a palliative approach* is offered by the Australian Government Department of Education and Training (2016a). This unit (CHCPAL001_R2) describes the specific skills and knowledge required for nursing assistants to care for people with life-threatening or life-limiting illness, or symptoms consistent with the normal ageing process, using a palliative approach (Community Services and Health Industry Skills Council, 2015). The elements of the unit are used to delineate the knowledge, skills and attitudes of nursing assistants in Australia in their provision of a palliative approach for two reasons. First, the unit was developed as part of the first National Palliative Care Strategy in 2000 to develop education curricula for workforce training using the World Health Organisation's definition of palliative care to develop resources (Australian Government Department of Health, 2016). Second, the *Guidelines for a palliative approach in residential aged care*

(Australian Government Department of Health, 2006) informed the development of the unit.

3.5.4 Essential knowledge and skills for nursing assistants

The performance criteria within the unit *Deliver care services using a palliative approach*, state that nursing assistants need to be to 1. Apply the principles and aims of a palliative approach when supporting individuals; 2. Respect preferences for quality of life choices; 3. Follow the person's advance care directives in the care plan. 4. Respond to signs of pain and other symptoms. 5. Follow end-of-life care strategies and, 6. Manage own emotional responses and ethical issues (Community Services and Health Industry Skills Council, 2015). The following studies were examined to see if nursing assistants were demonstrating these performance criteria.

Three key studies were conducted in residential care units in Sweden on the role of nursing assistants and their capacity to provide a palliative approach (Beck, Jakobsson, & Edberg, 2014; Beck, Tornquist, Bronstrom, et al., 2012; Beck, Törnquist, & Edberg, 2014). In the first, Beck, Tornquist & Bronstrom (2012) used an exploratory, descriptive research design to illuminate nursing assistants' experience in providing palliative care to older people across 13 RACFS. Focus groups were conducted with 25 participants, who identified themes related to the difficulties nursing assistants experience in providing quality palliative care, talking about death with relatives, and dealing with emotions. Only when residents were actively dying were nursing assistants able to focus on the resident's and family's needs and provide quality care. The study

illustrated, like previous studies by Chien (2010) and Waldrop & Nyquist, (2011) that there was conflict between balancing the needs of the resident, with expected procedures in the busy work setting and organisational culture of the RACF. In keeping with earlier findings by Ersek, Kraybill, & Hansberry, (1999), McDonnell, McGuigan, McElhinney, McTeggart, & McClure (2009) Whittaker et al., (2007), nursing assistants in the study by Beck et al. (2012) identified a lack of knowledge in providing emotional, supportive care, and experienced difficulty in discussing death and dying. They found it easier to provide physical care, despite wanting to engage in person-centred care. Training in communication is necessary to develop skilled and empathetic communication, and to be able to discuss the sensitive topic of dying and death; and, in fact, this is a core competency of palliative care (Australian Government Department of Health, 2014; Gamondi et al., 2013a). Without this training, nursing assistants are unable to provide the supportive emotional care that they are well placed to deliver.

As nursing assistants form close relationships with residents, they often perceive their resident's degree of pain more accurately than RNs or general practitioners (Cronfalk et al., 2015; Walker, 2007). The important role of nursing assistants in monitoring pain has been recognised on the basis that they may have known the resident for some years, are best placed to observe signs of distress during daily care provision and may make more sensitive pain assessments of cognitively impaired residents than those conducted by RNs (Liu, 2014; van Riesenbeck, Boerner, Barooah, & Burack, 2015). Their important role in the pain management of cognitively impaired older people is

based on their comprehensive, person-centred knowledge (McClement, Lobchuck, Chochinov, & Dean, 2010), but their supportive role in pain assessment and pain management has been found to be undervalued due to their scope of practice and the stigma attached to their role (Jansen et al., 2017; Liu, 2014). Nursing assistants' assessment of pain is undoubtedly becoming more important as resident–staff ratios change and there are fewer RNs in RACFs in a supervisory role (Mavromaras et al., 2017).

A very important skill, and one that is underpinned by knowledge and experience in nursing home staff, is the ability to detect when a resident is actively dying. Several studies have explored how aged care staff recognise when a resident is dying, including specifically how nursing assistants describe the signs of dying (Sahlberg-Blom, Hårsmar, & Österlind, 2013; Waldrop & Kirkendall, 2009; Waldrop & Nyquist, 2011). While nursing assistants have demonstrated expert behaviours in the care of dying residents, some staff have been found to be 'frightened', avoiding involvement with dying or deceased residents, 'leav[ing] cares to others' (Marshall, Clark, Sheward, & Allan, 2011, p. 692; McClement, Wowchuk, et al., 2009).

No explicit education on death preparation for nursing assistants was identified from any of the studies that informed this research. This indicates a potential gap in nursing assistants' education and training, whereby they may continue to be scared of facing the death of a resident or seeing a dead body when they commence their role (Cronfalk et al., 2015; Fryer et al., 2016). While this fear can be alleviated by working alongside more experienced nursing assistants

and by the acquisition of skills over time, experience in the RACF setting, although important, has not been found to be an effective alternative to education and training (Unroe et al., 2015).

In light of this finding, and with the objective of strengthening the role of nursing assistants in providing the best possible care at end of life, van Riesenbeck and colleagues (2015) identified variables which best prepare nursing assistants for residents' deaths. They compared characteristics of nursing assistants (n=140) and the context of care provision, specifically if there was support from co-workers and whether the resident was receiving palliative care described as 'hospice' within the study. Associations of preparedness outcomes and continuous variables in the nursing assistants' sample were analysed, including age, race, education, years of experience, time of shift, personal end-of-life care preferences, perception of residents' wishes at end of life, whether a resident was reported as experiencing pain, knowledge of care planning, perceptions of hospice, facility support, and emotional and informational preparedness. Results showed reported greater emotional preparedness in older, more experienced staff who sought support from co-workers, viewed palliative care positively, had a resident who had died while receiving a palliative approach (hospice) and who recognised pain in the resident. Informational preparedness was also associated with knowledge of the resident's and family's end-of-life care preferences. The authors were not able to determine whether those participants who felt better prepared for a resident's death were also better able to detect pain, or whether detecting residents in pain was an indicator of preparedness.

Nursing assistants also need to be able to manage emotional responses and ethical issues (Community Services and Health Industry Skills Council, 2015). Various studies have examined nursing assistants' grief experiences following the deaths of nursing home residents (Anderson & Gaugler, 2007; Funk, Waskiewich, & Stajduhar, 2014), communication in end-of-life care (Zheng & Temkin-Greener, 2010), and how nursing assistants deal with ethical issues at end of life (Chichin, Burack, et al., 2000; McClement, Lobchuck, et al., 2010). These studies lack specific data on what knowledge and skills participants possess so they can deal with issues as they arise, and how effectively they manage their emotional responses.

In a study by Burack and Chichin (2001) nursing assistants found it more difficult to care for a dying resident who had stopped life-sustaining treatment, such as a feeding tube, than to care for a resident who was dying from a disease over which they had no control. Ersek and colleagues also found that nursing assistants were distressed when residents were no longer tube fed, with some staff believing that residents were being 'starved to death' (1999, p. 578). The authors stated that as nursing assistants were usually excluded from discussions concerning goals of care, they might not have understood the treatment decisions or known if they were in accordance with the resident's wishes. Both of these studies were conducted in the United States before major educational initiatives were developed for aged care staff, including nursing assistants (Ersek & Wood, 2008; Kelly et al., 2008); however, similar questions included in Tool 2.1 (Eager et al., 2003) have been found to be problematic for Australian nursing assistants, suggesting that this level of worker lacks an

understanding or knowledge of the ethical dilemmas and decision-making which arise in caring for people with palliative care needs (Phillips, Davidson, Ollerton, et al., 2007; Phillips, Salamonson, et al., 2011). There is currently no content related to ethical decision-making in the Certificates in Individual Support/Ageing Support.

3.6 **Conceptual framework Summary**

The purpose of this study is the design, development and validation of an instrument to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach. A palliative approach relevant to the scope of practice of nursing assistants is the charter for what needs to be captured in the final instrument. The *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006) provide this charter and a conceptual framework for the content of the instrument and *Deliver care services using a palliative approach* informed by the *Guidelines*, specify criteria for nursing assistants' scope of practice.

The next section of this chapter discusses the ethical considerations applicable to this study and how these were managed.

3.7 **Ethical considerations**

As this study required human participants, ethics approval was sought from Western Sydney University's Human Research Ethics Committee prior to the study's commencement. The Ethics Committee ensures that research is carried out in accordance with the research code of practice, guided by the *National*

statement on ethical conduct in human research guidelines (Australian Government National Health and Medical Research Council, 2007) which applies across Australia. The potential benefits to participants in this study are that education and training result from changes attributed to findings from this research, with a secondary and very important benefit deriving from this: an improvement in the quality of care of older people in RACFs.

The research posed minimal risk to participants. In the final report, no ethical issues were raised by participants or participating organisations, and no one withdrew from the study. The approval number for this study is H9963.

Using the research ethics standards and guidelines, the researcher was mindful in all phases of the study to respect participants' autonomy, to demonstrate a respectful and consistent approach towards them, and to build trust by treating everyone in a careful and sensitive manner (Australian Government National Health and Medical Research Council, 2007). As the study sought to discuss the sensitive topic of death and dying within a palliative approach, the researcher needed to put in place resources to manage participants' potential stress. Other practices which the researcher used to adhere to ethical standards throughout the study included self-reflection and reflexivity following data collection; adherence to professional values, including confidentiality, maintaining the security of the data, and ensuring integrity in the reporting and presentation of the data.

Security of data is the legal, moral and ethical obligation of the researcher, who is responsible for restricting access to raw data by means of safe storage.

Arrangements for the secure storage of paper-based data were made with the researcher's school, and paper data was also stored in locked filing cabinets in the researcher's home office. Electronic data was stored on a password-protected laptop that was the property of the researcher, with back-up copies also kept at the researcher's home. Ethical responsibility with respect to the data also includes being mindful that permission must be obtained to use the data in any subsequent study, and that data needs to be destroyed after five years in accordance with university policy and code of practice. This is formulated in accordance with the key principles outlined in the Australian Code for Responsible Conduct of Research (Australian Government National Health and Medical Research Council, 2007).

3.7.1 Consent

As part of the process of gaining participants' consent, the researcher made participants aware of the voluntary nature of the study throughout the various phases of data collection. In Phase 1, the researcher organised an introductory visit with the facility's Director of Nursing (DON) to explain the study, to ensure participants had a proper grasp of time commitments, and to allow the opportunity to ask questions. Flyers and an information sheet explaining the study's aims were also provided to staff in participating facilities; these are presented in Appendix 2. While the voluntary nature of the study was emphasised, the researcher encouraged nursing assistants to participate by explaining the benefits of participation and the value of their contributions. At the same time as raising awareness about the nature and purpose of the study,

the researcher was mindful to allay any concerns about the research process.

In Phase 1, the researcher successfully sought permission to conduct the interviews in the workplace during work time and in a private space, to facilitate participation in the study and to allow participants the opportunity to speak freely. Subsequent phases were conducted both online using the web-based platform SurveyMonkey (http://www.surveymonkey.com) as well as paper-based surveys as a mode of administration in Phases 3 and 4. An information sheet explained the purpose of each phase of the study and concluded with information on the voluntary nature of participation. In the online version of the survey used to collect data in Phases 2, 3 and 4, opening the first page of the survey required participants to acknowledge that they understood their participation and agreed to proceed. Seeking consent in research is an essential component of the ethical and legal obligations of the researcher (Australian Government National Health and Medical Research Council, 2007). The researcher aimed to ensure that participants were autonomous and entered the study voluntarily. Each participant in all phases was advised that they could withdraw if they wished.

3.7.2 Confidentiality and anonymity

In accordance with the National Health and Medical Research Council ethical principles and research guidelines (2007), participants were advised that their confidentiality and individual identities would be protected. Specifically, participants involved in Phase 1 interviews were advised that data from the qualitative responses would only be used to derive themes and items for

questionnaire development, that findings would be aggregated, and any quotations used in the researcher's final thesis and journal articles would not contain any identifying information.

3.7.3 Participant support

While the likelihood of physical risk was considered minimal, emotional risks to participants were considered possible given the study's focus on a palliative approach and likely discussions about death and dying. The researcher anticipated a level of emotional risk due to the sensitive topic of residents' deaths and dying, and the benefit of providing information and resources on available bereavement and counselling services. Nursing assistants report feeling sad and stressed when caring for dying residents and in need of support (Anderson & Gaugler, 2007; Beck, Tornquist, & Bronstrom, et al., 2012; Marshall et al., 2011; Walker, 2007). Nursing assistants have demonstrated anticipatory grief as well as ongoing grief when discussing the loss of a loved resident (Walker, 2007), and there were indications of unmet bereavement support needs. For this reason, a list of counselling support services was provided as part of the information package delivered to the facilities in Phases 1, 3 and 4 (see Appendix 2).

3.8 Chapter summary

This chapter has presented the methodology and conceptual framework used in this study to develop an instrument to evaluate nursing assistants' knowledge, skills and attitudes within a palliative approach. The methodology section outlined the four-phase sequential mixed methods design and discussed the

rationale for the selection of this design. The conceptual framework used to inform the content of the study's instrument was described, detailing the relevant elements for nursing assistants' scope of practice. The chapter also presented the ethical considerations applicable to the study and discussed how these were managed. The following chapter provides a detailed account of Phase 1 data collection and data analysis methods and presents the phase's findings.

Chapter 4 Phase 1: Item Generation

4.1 Overview

The previous chapter outlined the study's methodology and conceptual framework and described the four phases undertaken to develop the instrument. This chapter presents the aim, data collection method, sample and setting for Phase 1. In this phase, a qualitative approach with thematic analysis was used to generate data. The significance of this approach to the instrument development process is discussed. The chapter outlines the process of category development and item generation and provides a sample of items from each category accompanied by the overall results for each of the key attributes of knowledge, skills and attitudes. The last section provides an overview of how the finalised items were formatted into an online survey to enable content validation by experts in the next phase.

4.2 Aim

The aim of Phase 1 was to generate a broad pool of items encompassing the construct of a palliative approach for the development of the instrument. Exploring a construct with the target population is considered an important aspect of instrument development and strengthens the content and construct validity requirements of a new instrument (DeVellis, 2012; Polit & Yang, 2016; Streiner & Norman, 2008). Items generated from qualitative data ensure relevancy and can be used to reflect the everyday language used by participants (DeVellis, 2012; Oppenheim, 2005; Rattray & Jones, 2007).

4.3 Sample and setting

Participants in Phase 1 were a purposive sample of nursing assistants (n=25) employed in three residential aged care facilities (RACFs). The decision to use sampling from multiple sites was to increase heterogeneity, which Polit and Yang (2016) advocate to improve the construct and content validity of an instrument.

Three RACFs were selected: two were for-profit organisations, one a large national organisation with multiple facilities (Site A) and the second one of three state-based facilities in NSW (site B). The third RACF belongs to a large national, not-for-profit, religious organisation and is also an accredited dementia-specific facility (site C). Sites were limited to two local health districts in the Western and South Western metropolitan areas of Greater Sydney whose communities are the most socially, economically, culturally and linguistically diverse, with identified challenges related to population growth and ageing (New South Wales Ministry of Health, 2016).

4.3.1 Sample size

The sample size was initially determined by the number of nursing assistants who volunteered for an interview at each site. At the researcher's first visit, eight participants volunteered for interview at site A, six at site B and eleven at site C.

Small samples are generally a feature of qualitative research and it has been suggested that approximately twelve cases is sufficient for the development of

descriptive categories (Bazeley, 2013), although a case is also made for larger sample sizes (20–30+) when the free flow of data is circumscribed, as is the case in semi-structured interviewing, and if an analytic strategy, for example, is to be used to quantify the data (McIntosh & Morse, 2015; Morse, 2015). The final determinant of sample size when thematic analysis is being used is having fully developed categories to which no new information can be added (Bazeley, 2013). The sample in this study was one homogenous occupational group of nursing assistants, yet there was sufficient diversity within the group (discussed below) to warrant a larger sample to ensure no minority voice or opinion was missed (McIntosh & Morse, 2015).

A total of 25 nursing assistants made up the sample for data collection in Phase 1. This number is similar to that found in other qualitative studies, including those conducted with nursing assistants (Beck, Tornquist, Bronstrom, et al., 2012).

4.3.2 Inclusion criteria

All nursing assistants employed in the RACFs and who provided direct care to residents were eligible to participate. Direct care describes the hands-on personal and physical care provided by staff to a resident or patient, as distinct from administrative or management duties (Mavromaras et al., 2017). Interviews were conducted during business hours to maximise participation. Participants who worked the morning shift (0700–1300 or 0700–1530) were recruited. Table 5 presents the percentage of nursing assistants who participated in Phase 1, from the total number of nursing assistants employed

in each facility.

Table 5

Percentage of sample to total population in each RACF

Variables (N)	Site A	Site B	Site C
Residential places	152	80	96
Nursing assistants	95	50	60
Interviews	8	6	11
% total staff	8.4	12	18.3

4.4 Method

4.4.1 Data collection phase 1

The researcher contacted the care managers or DONs of the three RACFs by phone in the first instance, to introduce the study and ascertain interest. Meetings were organised to discuss the Phase 1 component of the study in detail and to provide the information flyer and participant information sheets outlining the study (Appendix 2) in Phase 1. The information sheet advised the time the interviews were expected to take, outlined the benefits of participation in the study and explained that data collected from the interview would be treated confidentially. Once the DON or care manager gave permission to conduct the study, a date was arranged for the on-site interviews.

4.4.2 Pilot interviews

Pilot interviews were conducted prior to data collection with the target sample for several reasons. First, pilot interviews allow the researcher to run through

the interview process and practice asking the questions; second, they provide an opportunity to determine any problems with the questions; and third, they give some gauge of how long the questions might take participants to answer. Pilot interviews are recommended for these reasons to test the interview process (Turner, 2010).

The pilot interviews were conducted with two community ENs, both of whom had more than ten years' experience in the field, with exposure to community clients with palliative care needs. Feedback from the interviews was positive and confirmed the comprehensibility of the questions. The length of each interview was approximately 30 minutes, which was the time suggested on the participant flyer (Appendix 2).

4.4.3 Interview schedule

The interview schedule for Phase 1 participants was designed around the key attributes that were to make up the new instrument. A broad introductory question introduced the topic, followed by open questions designed to tap into participants' understandings and views, and specifically to identify the knowledge, skills and attitudes they considered important in providing care with a palliative approach. The first set of questions explored essential knowledge and experience; the second set addressed motivation and feelings, and the third set addressed skills. Feedback on the interview schedule was provided by the researcher's supervisory team; the schedule is presented in Appendix 4.

4.4.4 Semi-structured interviews

A semi-structured interview was adopted in the first instance. This data collection strategy is used when there is a body of objective knowledge about the phenomenon or construct but limited subjective knowledge (McIntosh & Morse, 2015). As the aim of this phase was to understand the construct of a palliative approach from the perspective of nursing assistants, a standardised approach using the semi-structured interview method was used to guide the researcher in eliciting information without disturbing, influencing or biasing participants' responses (Gubrium & Holstein, 2001). This was an important consideration, as the researcher is a clinician in palliative care and immersed in the phenomenon being studied. Broad, open-ended questions and the stance of 'not knowing' was adopted to encourage participants to talk freely, and the interview questions also focused participants' responses on the topic of inquiry (McIntosh & Morse, 2015).

4.4.5 The interview process

The interviews (n=24) were conducted over a seven-week period in early 2013. One interview at Site C was a joint interview with two nursing assistants, at the participants' request. They informed the researcher that as nursing assistants generally work together, they could not continue their work effectively without their partner. To facilitate this interview and in an attempt to limit the influence of one participant over the other, questions were asked of these participants in an alternating sequence. The average length of initial interviews was 12 minutes (range 8-18 minutes).

Participants were informed by the team leader that interviews were in progress and they could attend when they had finished their work with the residents. In all sites, participation was facilitated by the participants themselves. In what has been described as 'wholesale access' (Miller & Bell, 2012, p. 69), each participant on finishing his/her interview organised the next participant. As each participant presented for interview, the researcher explained the research project, gave an overview of what Phase 1 entailed, emphasised the important contribution of participants in this phase of the study, and provided the participant with the participant information sheet (Appendix 3) and consent form (Appendix 3).

4.4.6 Data saturation

Interviews continued until data saturation had taken place. After 24 interviews (including one interview with two participants, described above), it was evident that no new themes corresponding to the construct were being generated: an indication that data saturation had been reached (Bazeley, 2013). The researcher deemed this to be the logical place to stop collecting interview data.

There are different meanings attributed to data saturation (O'Reilly & Parker, 2013; Serry & Liamputtong, 2010; Glaser & Strauss, 1967). To ensure quality and rigour, data needs to capture a range of experiences and opinions. Equally important is the transparency of the process of determining that saturation has been reached (O'Reilly & Parker, 2013). In the analysis of whether saturation had been reached in this phase of the study, the comparative process of interpreting the data which the researcher had been engaged in from the first to

the last interview, through the various stages of listening, note taking, transcribing, reading, reviewing and reflecting, ensured intimate knowledge of the data. A discussion with the researcher's supervisors supported the decision on data saturation related to the interview schedule.

4.4.7 In-depth Interviewing

After a review of two of the initial transcripts by the researcher's principal supervisor, the decision was taken to deepen and build the data in follow-up interviews, using in-depth interviewing, which would also provide an opportunity for participants to check the data. A return visit to conduct these interviews was organised with the facility managers. Follow-up interviews provided an opportunity for participants to check their transcripts, to agree or disagree with the data and to expand upon earlier statements (Patterson, 1995).

An in-depth approach was adopted with participants whose transcripts indicated that further exploration of the research themes might yield more detailed data (Patterson, 1995; Tan, O'Connor, Howard, Workman, & O'Connor, 2013). In-depth interviewing offers an alternative approach to semi-structured interviewing and can also counter the possibility of researcher bias by using an initial probing structure: the strength of this approach is the depth of data generated by the 'insider perspective' (Serry & Liamputtong, 2010).

The researcher's approach in these follow -up interviews, influenced by Patterson (1995), entailed asking the participants to read their first interview transcripts. This provided an opportunity for them to check the content of their

first interview (Ezzy, 2002). Participants were asked if they wanted to clarify, agree or disagree with anything that they had said in their interview. The researcher then reviewed the data with the participants, using the exact phrases they had used, and asked them to give examples or to explain further the meaning of their original statements.

Participants were encouraged to identify any important questions that the researcher had missed in the first interview. To prompt responses to the question of what might have been missed, and to further probe the construct of a palliative approach, an additional question was asked of participants at the conclusion of each follow-up, in-depth interview:

> If your employer were to offer education in a palliative approach, what are the areas you believe you need?

4.4.8 Identification of participants for follow-up interviews

For the follow-up interviews, the researcher identified participants who had provided detailed or 'thick description' in their initial interview (Denzin, 1989, in Bazeley, 2013). These participants had expressed views and opinions that indicated that they were either knowledgeable or experienced in their role; or they had seemed to want to discuss the questions in greater detail, or they appeared to be the most 'enculturated' in their setting (Geertz 1973, in J. M. Johnson, 2001, p. 111). An open-ended approach to the follow-up interviews is described as a way to promote self-understanding by allowing participants to talk freely and ascribe meanings (Silverman, 2013); this approach privileges the participant as 'knower' and informant providing their understanding of the

inquiry (McIntosh & Morse, 2015).

Twelve follow-up interviews were conducted between April and August 2013. These were longer than the original interviews and took from 19 minutes to 48 minutes; all were recorded with participants' consent.

4.5 Reflexivity in Research

The researcher adopted the practice of reflexivity to self-reflect on the exchanges that had taken place during the research encounters and to acknowledge her role in the data collection process. This is necessary because of the potential influence of a researcher's own political and personal perspectives may have on research (Gillies & Alldred, 2012). While there are a number of views about the meaning of reflexivity in qualitative research (Berger, 2015; Jootun, McGhee, & Marland, 2009; McCabe & Holmes, 2009), it is commonly described as a strategy to combat biases and imbue sensitivity, trustworthiness and transparency. As such, reflexivity instils rigour into the qualitative research process.

To promote a stance of reflexivity, thoughts and impressions were recorded after each exchange with participants, in an attempt to capture personal perspectives, attitudes and opinions expressed by participants during the interview. These analytic notes were written about these thoughts and experiences, including how a participant's comments provided an insightfulness and explicitness of opinion which contrasted with and contextualised the objective 'knowledge' provided by authoritative sources on residential aged care, such as can be found in the Australian Institute of Health and Welfare's

statistical reports, one of the sources informing this study (Australian Institute of Health and Welfare, 2016).

Reflexivity includes thinking about the relationship between the researcher and the participants (Jootun et al., 2009; Pleschberger, 2007). It includes being aware of how factors such as the context and setting of interviews may shape the data, how participants are accessed in the research, how the researcher and participant are positioned in terms of power within the research relationship—all of which influence the construction of the data (Miller, 2012; Miller & Bell, 2012). This was an opportunity for the researcher to internalise the importance of informed consent, privacy and confidentiality and the notion of 'wholesale access' to confirm that the entire research was ethically conducted.

4.6 Data analysis

While data collection provided this element of reflexivity, transcribing the interviews was a second opportunity to reflect further on these issues (Ezzy, 2002). Data analysis commenced following the first series of interviews, as is recommended (Bazeley, 2013; Ezzy, 2002). From the outset, deductive reasoning was applied to the data to identify the objective knowledge of the construct using the study's conceptual framework. In this approach, the researcher is active in the analytic process, interpreting and summarising explicit or surface meanings and analysing the data on the basis of existing knowledge (V. Braun & Clarke, 2006; Eto & Kyngäs, 2008). A priori knowledge relates to already agreed-upon professional definitions which are expressed in the literature, the body of objective knowledge (Ryan & Bernard, 2003). In this

study, the *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006), the educational unit *Deliver care services using a palliative approach* (Community Services and Health Industry Skills Council, 2015), and the wider literature formed this a priori knowledge, providing the conceptual framework of the study. A deductive approach was an appropriate method for analysis on the basis that a palliative approach is a recognised framework with core competencies related to knowledge, skills and attitudes (Australian Government Department of Health, 2006, 2016; Gamondi et al., 2013).

4.6.1 Demographic data

The sample of 25 nursing assistants recruited for Phase 1 shows a diverse group of participants employed across the three RACFs, and representative of the study population. Participants were mostly female (84%) and culturally and linguistically diverse, coming from many ethnic backgrounds. There was a wide range of age groups across the sample with a median age range of 31–40, which indicates a younger residential aged care workforce compared to that found in previous workforce surveys (Mavromaras et al., 2017). Participants had a range of experience in the role, with an equal number of nursing assistants with less than one years' experience and those with more than ten years' experience. A majority indicated that they had 5–10 years' experience as a nursing assistant. Most participants (n=21) had attained Certificate III in Aged Care, which is consistent with the general population of nursing assistants (Mavromaras et al., 2017). Half the sample (n=12) had worked in their current workplace for more

than five years, representative of the largely stable residential aged care workforce (Mavromaras et al., 2017). Interestingly, the majority of participants (84%) indicated that this was their first job in aged care. Five reported they had transferred across industries and professions, including business (accounting and industrial), child care, and administration. Table 6 provides the demographic profile of the sample.

Table 6

Demographic Characteristics of Sample in Phase 1

Characteristics sampled	**Variation within characteristic**	**Number of participants (n=25)**	**%**
Gender	Female	21	84.0
	Male	4	16.0
Age	18-24	3	12.0
	25-30	3	12.0
	31-40	11	44.0
	41-50	4	16.0
	51-60	3	12.0
	61-70	-	-
	missing	1	-
Language spoken at home	Albanian	1	4.0
	Arabic	1	4.0
	Bengali	1	4.0
	Chinese	1	4.0
	English	7	28.0
	Hindi	5	20.0
	Punjabi	4	16.0
	Russian	1	4.0
	Samoan	1	4.0
	Spanish	1	4.0

	Tagalog	2	8.0
Duration of employment as a nursing assistant	< 1 year	4	16.0
	1-2 years	5	20.0
	2-3 years	2	8.0
	3-5 years	3	12.0
	5-10 years	7	28.0
	>10 years	4	16.0
First job in aged care	Yes	21	84.0
	No	3	16.0
	missing	1	
Length of time in current workplace	< 1 year	4	16.0
	1-2 years	5	20.0
	3-5 years	3	12.0
	6-10 years	7	28.0
	11-15 years	3	12.0
	>16 years	2	8.0
Qualification	Certificate III Aged Care	21	84.0
	Certificate IV Aged Care	8	32.0
	Undergraduate nursing	3	12.0
	Nursing education	2	8.0
	Other non-nursing	2	8.0

4.6.2 Transcription

Twenty-four initial interviews and ten follow-up interviews required transcription. To begin data analysis, the researcher transcribed the first 18 interviews from voice to text and these were checked for accuracy against the audio recording. The transcription documents retained the coding used during data collection to preserve anonymity. These codes represented the site and participant (e.g. 101: the first participant at the first site). The six remaining

interviews and ten of the follow-up interviews (detailed below) were transcribed externally because of time constraints and the ongoing process of data analysis. All outsourced transcripts were checked by the researcher against the original audio recording and read through carefully. When each interview had been transcribed, the researcher reviewed each one while listening to the recording, re-familiarising herself with the data. At this point the data was ready for allocation to one of the three broad themes: knowledge, skills and attitudes, the domains of the new instrument.

4.6.3 Knowledge

Knowledge data was identified as an articulation of awareness or understanding of the construct of a palliative approach. It is defined as both a theoretical and practical understanding of a construct or subject (Oxford English Dictionary, 2013). Nursing knowledge includes 'lay knowledge' or 'everyday knowing' (Cribb, 2009) which includes 'tacit' knowledge, the intuitive knowledge that develops through experience and practice, as well as more specialised nursing knowledge and scope of practice (Benner, 1982; Burnard, 1989). Knowledge data was distinguished from skills and attitudinal data insofar as it indicated the participant's cognitive understanding of the construct of a palliative approach.

4.6.4 Skills

Skills data was identified when participants reported their actions, or 'doing' when providing a palliative approach. Skills reflect behaviour and action and generally enable a person to be competent in what they do. They are an

essential attribute for competency within total performance (Nursing and Midwifery Board of Australia, 2015). Skill-based competency is an integration of many attributes, including cognitive, affective and psychomotor functions, and is linked to effective performance of a task in the context of an identified work role (Australian Government Department of Education and Training, 2013).

Skills for nursing assistants include preparation, technique, and approach to the task being undertaken, as well as judgement, communication and teamwork (Australian Government Department of Education and Training, 2013). Care behaviours or care strategies have been identified in the literature to describe what nursing assistants do when providing a palliative approach (Beck, Tornquist, & Bronstrom, et al., 2012; McClement, Wowchuk, et al., 2009). When data indicated action related to any of these functions, the data was allocated to skills.

4.6.5 Attitudes

Attitudinal data was identified when participants expressed views, beliefs and opinions reflecting a personal judgement about something's truth or desirability (Schofield & Knauss, 2010). 'Attitude strength' is a term used to determine those attributes of attitude that indicate whether the attitude is likely to be stable or to fluctuate over time (Visser, Bizer, & Krosnick, 2006). Whether an instrument can adequately quantify attitude when no single structure can be identified has been acknowledged (Brown et al., 2015). In this study, data was allocated to the theme of attitude when it reflected personal

thoughts and beliefs, affective or emotional information (Zanna & Rempel, 1988).

4.6.6 Procedure for extracting data

Tables were constructed in Microsoft Word for each interview, and all data was allocated to one of three columns: knowledge, skills or attitudes. Colour coding was also used to highlight different themes: red for knowledge, blue for skills, and yellow for attitudes. The researcher examined the data to determine which of the three themes the data belonged to by asking the question: 'what is this an expression of?', an approach used in the constant comparative method by Glaser and Strauss to generate and suggest categories, properties and hypotheses about general problems (1967, p. 104). All data was allocated to one of the theme columns.

4.6.7 Data allocation

All data from each transcript was allocated to one of the three themes. Data was extracted from each transcript and imported into a separate document for each theme. Data was then grouped in categories according to key words, or in natural clusters of similar words or meanings. This grouping was based on the researcher's interpretation of the meaning of the data, using the a priori themes for a palliative approach derived from the literature.

4.7 Item Generation

4.7.1 Knowledge items

Data related to knowledge was the first theme to be elicited from participants' responses and categorised according to key words or data that naturally clustered with similar words or meanings. The clusters were named according to the a priori defined categories identified in the *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006). This resulted in the identification of eight categories: 1. a palliative approach; 2. physical symptoms—assessment and management; 3. family support; 4. social support; 5. cultural issues; 6. end of life; 7. team approach; 8. professional development. An iterative process, going back and forth reviewing the data, confirmed the placement of items in each category (Vaismoradi, Turunen, & Bondas, 2013). From these groupings, question items began to emerge, connected to the data and stemming from the 'voices' of nursing assistants. These questions were designed to incorporate all knowledge data; they can be seen in their entirety in Appendix 5.

The following sections provide examples of knowledge items generated from the data.

4.7.1.1 Category 1: a palliative approach

Data from this first category describes nursing assistants' understanding of the construct 'a palliative approach'. One hundred and fifteen initial items were generated from this data. An example of a question generated from the data is

shown below:

Category 1: A palliative approach	**Question**
101.2.2 A palliative approach to me is letting someone go comfortably, that's probably the best way to explain it 101.26.2 I mean to me, palliative means 'goodbye', go comfortable 101.64 allowing a person to go peacefully, pain free and with dignity 102.6 but at the end of the day, it's all about trying to keep them happy and comfortable	The main aim of a palliative approach is enabling a person to die pain free and with dignity?

4.7.1.2 Category 2: physical symptoms: assessment and management

Data from the second category describes awareness and knowledge of a resident status. Thirty-four initial items were generated from this data. An example of a question generated from the data is shown below:

Category 2: Physical Symptoms—Assessment and Management	**Question**
308.35 I think assessing the patient is one of that 308.39 it's physically the colours of the patient, the breathing—physically. That's how we assess them. That's—we actually tell the sisters—the RN in charge. Straight away we have to tell them—inform them so the doctors will come and check the patient 308.79 They just don't know the terminology of that or they just don't know what's causing that but they know straightaway. But some of them they've been here for 20 years … so if a patient's colour[s] turn different or if the patient [has a] swollen arm, they	Observing physical changes in a person can be the first step in managing symptoms?

know straight away, they tell the RN

4.7.1.3 Category 3: family support

Data from the third category identifies the needs of families, addressing families' concerns and the provision of information by nursing assistants. Twelve initial items were generated from this data. An example of a question generated from the data is shown below:

Category 3: Family Support	**Question**
101.47 when they do tell them that, they can see, yes, it is but then you go, these are the things we can put in place while this is going on and these are the people who can help you, you know, then people have got more of … [pause] an open mind 308.63 if the patient, family member is dying, it's very hard for the family members to understand the situation, they're still in denial, but if you actually explain to them that everything is going to be like this	When families understand what is happening, they cope better?

4.7.1.4 Category 4: social support

Data from the fourth category describes knowledge of social support needs of residents. Six initial items were generated from this data. An example of a question generated from the data is shown below:

Category 4: Social Support	**Question**
301.7 Getting them out and socialising with others, especially if they're depressed or loneliness [sic], just to get them to know other people so they're not	Assisting a person to socialise helps with loneliness?

feeling that loneliness. 301.29 Some patients are lonely, you talk to them. It's really interesting what they have to say. You never know what they're going through unless you ask.

4.7.1.5 Category 5: cultural awareness

Data from category five describes cultural awareness. Four initial items were generated from this data. An example of a question generated from the data is shown below:

Category 5: Cultural awareness	**Question**
301.5. … just to be aware of the different cultures and knowing the different cultures so that they don't do something wrong to the patient, I guess. 301.37 all cultures are different so you have to respect that. They might prefer to wear something, you know, their cultural clothing or something like that during the day and you have to be aware of that and just communicating with others so they know as well	Taking the time to find out the cultural preferences of a person is a way of giving individualised care?

4.7.1.6 Category 6: team approach

Data from the sixth category describes working in a team and the value of a team approach. Twelve initial items were generated from this data. An example of a question generated from the data is shown below:

Category 6: Team approach	**Question**
308.14 There is a team who actually talk to the family. What do they want to improve more? Or do they have any concern to the resident? So we actually	A team approach can improve the quality of a person's care?

discuss that.

4.7.1.7 Category 7: end of life

Data from category seven describes awareness and knowledge about death and dying. Fifteen initial items were generated from this data. An example of a question generated from the data is shown below:

Category 7: End of life	**Question**
101.50 even really demented residents have moments of clarity, you can see it, and hear it, see it and all of a sudden, they get a changed look and they'll just look at you and go, 'I want to die, just let me go', or 'why can't I do this?', they're really clear about it … each time the person's always died within a month	A person's wish to die means that the person will die soon?

4.7.1.8 Category 8: professional development

Data from category nine describes the issues related to professional development: educational and training needs. Five initial items were generated from this data. An example of a question generated from the data is shown below:

Category 8: Professional development	**Question**
105.6.3 We need to have a little bit more preparation beforehand instead of learning it as we go. Because sometimes, palliative care, they're here for a long time, other times they're only here for a couple of days. So, if you know a bit more, that gives you that time before instead of after	Carers don't need professional development if they are able to learn on the job?

4.7.2 Skills items

Next, data related to skills was elicited from participant responses and categorised. As with the knowledge data, data that naturally clustered with similar words or meanings was grouped. The clusters were named according to their fit with a priori themes. An iterative process confirmed data that belonged together. This process resulted in the identification of eight skill items categories: 1. Observing and Documenting 2. Providing Physical Comfort 3. Managing Pain and Symptom 4. Supporting Families 5. Adopting a Team Approach 6. Providing End-of-Life Care 7. Providing Social Care and 8. Professional Development and Reflection. Skill items were developed to incorporate all of the skill data and were formatted in the first person voice to reflect what nursing assistants do when providing care with a palliative approach. A total number of 63 preliminary skill items were generated across the eight categories (see Appendix 5).

The following section provides examples of skills items generated from the data.

4.7.2.1 Category 1: observing and documenting

Data from the first category identifies skills in observing and documenting. Eleven initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 1: Observing and Documenting	**Statement**
307.36 skills is … follow whatever is in the care plans according to their illness or disease, whatever they	I provide care according to

are going through, and provide support according to that.	an individual's care plan.

4.7.2.2 Category 2: providing physical comfort

Data from category two identifies skills in providing physical comfort. Eight initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 2: Providing Physical Comfort	**Statement**
201.26 As long as person can't feed themselves but they can still eat, whoever is looking after them you try your best to feed them, however much they can eat. If someone doesn't eat at all, they've given up, so you talk to their family and explain what's their condition and sometimes families put them on a peg tube while others just want them to go and be—and they agree with the decision, what they've made	I observe an individual's ability to feed themselves.

4.7.2.3 Category 3: managing pain and symptoms

Data from category three identifies skills in managing pain and other symptoms. Nine initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 3: Managing Pain and Symptoms	**Statement**
202.41 … when we—if somebody [unclear word] pain they make their face and sometimes the noise, I don't know exact word … Some are still speaking but oh, 'I've got pain', you know.	I observe for pain when I provide care.

4.7.2.4 Category 4: supporting families

Data from category four identifies skills in supporting families. Five initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 4: Supporting Families	**Statement**
301.25 We talk to a lot of families about anything and we listen. Most of the time all we do is listen. We don't want to say something to—that is wrong so all we do is listen and a lot of them appreciate just listening	I support families by addressing their concerns.

4.7.2.5 Category 5: adopting a team approach

Data from category five identifies skills in using a team approach. Eight initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 5: Adopting a Team Approach	**Statement**
101.7.2 We've got to be able to speak our opinions and we've got to be heard. Yes, we're only AINs, but we're the ones who deal with them day to day	I contribute to problem-solving to seek solutions.

4.7.2.6 Category 6: providing end-of-life care

Data from category six identifies skills in provision of end-of-life care. Six initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 6: Providing End-of-life care	Statement
202.66 first time you feel scared, you don t want to see, but I don't know, now is okay. Some are still—some staff, they don't want, they can't handle … death, after death	I provide post-mortem care.

4.7.2.7 Category 7: providing social care

Data from category seven identifies skills in providing social care. Twelve initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 7: Providing Social Care	Statement
304.14 to get residents to keep their quality of life, to get them to move around, to try and feed themselves	I encourage independence.

4.7.2.8 Category 8: Professional development and reflection

Data from category eight identifies skills in professional development and reflection. Four initial skills statements were generated from this data. An example of a skills statement generated from the data is as follows:

Category 8: Professional development and reflection	Statement
105.24 the first time I've ever come across a trache[ostomy]. I had no idea, no idea what to do, so I was lucky that my partner had more experience and could show me, pass that knowledge on to me, but still, I would be, [sic] cause it was only for a short time, if that situation came up again I wouldn't be confident enough to pass that on, I haven't had enough, yeh. I'd have to rely on more	When I am unsure how to do something, I seek advice.

training or somebody with that knowledge to be with me

4.7.3 Attitude Items

Finally, data related to attitudes was elicited from participant responses. This data was grouped in categories according to key words or data that naturally clustered with similar words or meanings; this grouping was based on the researcher's interpretation of the meaning of the data. The groupings were named according to the overall interpretation and fit with a priori themes. An iterative process confirmed that data belonged together. This process resulted in the identification of eight attitudinal items categories: 1. a palliative approach; 2. physical symptoms—assessment and management; 3. family support; 4. social care; 5. end-of-life care; 6. professional development and reflection. Attitudinal items were then developed to incorporate all of the attitudinal data. A total of 48 attitudinal statements were generated from the eight categories (see Appendix 5).

The following section provides examples of attitudinal statements generated from the data.

4.7.3.1 Category 1: a palliative approach

Data from the first category describes attitudes towards a palliative approach. Twenty-one initial attitudinal statements were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 1: A Palliative Approach	Statement
101.2 The ones who have no quality of life; the fact that they're stuck in a bed, or stuck in a chair, they can't speak, they're on a peg feed, it's not good	A palliative approach can help improve a person's quality of life.

4.7.3.2 Category 2: physical symptoms: assessment and management

Data from category five identifies attitudes towards pain and symptom management. Three initial attitudinal items were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 2: Pain and Symptom Management	Statement
308.73 They [the RN] do ask: how much is your pain, basic, you know what did they learn in university, like how much is your pain, tell me where is your pain, can you please describe your pain, simple that's it. But if you actually go there, talk to them, if you have time to communicate with them, you show them that you're there for them	I have a role to play in pain management.

4.7.3.3 Category 3: family support

Data from category three identifies attitudes towards families. Four initial attitudes statements were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 3: Family Support	Statement
102.51 … it's prolonging their (pause) what's the inevitable. I mean they're	In a palliative approach, families need my support.

suffering, the families are suffering so just try and relate to what we're saying. Think of us, we're the nurses we know so it's whether the families can adapt to it. But I think if you explain it to them the best way you can, then they'll go with you

4.7.3.4 Category 4: social care

Data from category four identifies attitudes towards the provision of social care. Seven initial attitudinal items were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 4: Social Care	**Statement**
311.24 I go to the resident and she likes reading story books. Then in my spare time, if I have nothing to do, I have to spend time with my residents. So when I go with her, I just read with her, share with her what's in this book, and make them happy. Also like I'll ask her about— other residents like watching TV and there's a favourite program like maybe *Home and Away*, whatever. I tell them a story about them and all this to make [her]happy so that she can refresh her mind	In a palliative approach, I think about the person holistically.

4.7.3.5 Category 5: end-of-life care

Data from category five identifies attitudes towards end-of-life care. Five initial attitudinal items were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 5: End-of-Life Care	Statement
102.23 … But when they're sick and they're dying all they just need is just tender loving care. Just that hands on, that touchy feely. If they haven't got any family they don't want to die alone. They don't. So just touching them and being there with them	I am able to provide comfort when a person is dying.

4.7.3.6 Category 6: professional development and reflection

Data from category eight identifies attitudes towards professional development and self-reflection. Two initial attitudinal items were generated from this data. An example of an attitudinal statement generated from this data is shown below:

Category 6: Professional Development and Reflection	Statement
104.7. If you do the things most of the time, I think that's enough experience, so that you gain a lot of experience so that in the future you know how to handle different types of residents.	In a palliative approach professional development is not necessary when care providers can learn on the job.

4.8 Results

This next section presents the results of the item generation process for each of the three attributes of knowledge, skills and attitudes. Table 7 summarises the knowledge categories and the number (%) of preliminary and finalised items for each category.

4.8.1 Knowledge items

An initial 194 knowledge items (see Appendix 5) were allocated to one of eight categories identified from the conceptual framework of the *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006). A process of review and refinement reduced the number (%) of preliminary items, as shown in Table 7.

Table 7
Knowledge items across knowledge categories

Category	**Preliminary items**	**%**	**Final items**	**%**
A Palliative Approach	106	55	21	41
Physical Symptoms (Assessment and Management)	34	18	13	25
Family Support	12	6	3	6
Category	**Preliminary items**	**%**	**Final items**	**%**
Social Support	6	3	3	6
Cultural Issues	4	2	2	4
End of Life	15	8	2	4
Team Approach	12	6	5	10
Professional Development	5	2	2	4
Total items	194	100	51	100

4.8.2 Refinement of knowledge items

Clark and Watson (1995) and DeVellis (2012) recommend that an item pool be as large as possible to encompass the construct of interest and to include broad and comprehensive items that are over-inclusive. Repetitive items, while

creating an appearance of redundancy, can strengthen an instrument's internal validity by representing or expressing the underlying phenomenon of interest in different ways (DeVellis, 2012). Adopting this recommendation resulted in an initial item pool of 194 items accounting for all the data pertaining to knowledge within the eight categories (see Appendix 5). Items can be eliminated if the pool is too large for ease of administration and likely to burden participants (DeVellis, 2012). For this reason, a process of review and refinement was undertaken to determine the best items for inclusion in the development instrument for content review in Phase 2.

The researcher and supervision team reviewed the knowledge questions at length, refining and deleting repetitive items using the following specific criteria: items lacked clarity or specificity of construct, were overly repetitive or too similar to other items, could not easily be expressed in a different way without convolution, or did not add value; items that were not readily identifiable as facts (could not be easily supported by the *Guidelines* [Australian Government Department of Health, 2006]) or the literature, or did not lend themselves to a true/false format.

Examples of items deleted for not being identifiable as facts or specific to a construct included the following:

- denial is a way that some family members use to avoid the reality of dying
- routine is important for people with dementia.

In this process, two items that appeared to reflect attitudes were allocated to the category 'palliative approach' within the 'attitude' data:

- In a palliative approach, people are best cared for in bed.
- People who benefit most from a palliative approach are unable to do anything on their own.

A further 141 items were deleted based on the above mentioned criteria. Removal of these items yielded the number for each category shown in Table 7. Fifty-one reviewed and refined knowledge items (see Appendix 6) remained for the next phase of the study, content validation by experts.

4.8.3 Item difficulty

To ensure that the 51 knowledge items were able to discriminate level of knowledge, from poor to excellent, within the target population of nursing assistants, they were stratified across all categories, where possible, to include a mix of easy, moderately difficult, and difficult items, determined by the following criteria:

Easy	'Commonsense' understanding and awareness (Cribb, 2009); content included in *Deliver care service using a palliative approach* (Australian Government Department of Education and Training, 2013)
Moderately difficult	Content included in *Deliver care service using a palliative approach* plus experience in role (Benner, 1982; Burnard, 1989).
Difficult	Content not included in *Deliver care service using a palliative approach*; requires extensive experience in role and further training and development (Benner, 1982).

4.8.4 Skills items

Skills items were allocated to one of eight categories based on a priori themes aligning with the categories from the *Guidelines* (Australian Government Department of Health, 2006). The 63 skill items generated from the data are shown in Appendix 5. Table 8 summarises the skills categories and the number (%) of skills items.

Table 8

Skills items across skills categories

	Category	**Preliminary items**	**%**	**Finalised items**	**%**
1.	Observing and Documenting	11	17	5	10
2.	Providing Physical Comfort	8	13	7	15
	Category	Preliminary items	%	Finalised items	%
3.	Managing Pain and Symptoms	9	14	10	21
4.	Meeting the Needs of Families	5	8	4	8
5.	Adopting a Team Approach	8	13	7	15
6.	Providing End-of-Life Care	5	10	5	10
7.	Providing Social care	12	19	5	10
8.	Professional Development and Reflection	4	6	5	10
	Total Items	63	100	48	100

4.8.5 Refinement of skills items

The process of review and item refinement by the researcher and supervision team resulted in the elimination of 18 items. These items were duplicates (n=2),

not specific to the construct of a palliative approach (n=12), were double- or triple-barrelled (grouping two or three words with different meanings) (n=1) or overlapped with an attitudinal item (n=3).

Three statements were moved to the attitude categories:

- I support an individual to feel at home
- I encourage independence
- I maintain dignity at all times when providing care

The following items were transferred from the attitudes to the skills category:

- I am able to maintain a work-life balance for my own wellbeing.
- I learn how to provide a palliative approach by doing

Following this process, 48 skills items were retained for content validation by experts in Phase 2 of the study (see Appendix 6).

4.8.6 Attitude items

Six categories based on a priori themes in the literature were used to generate attitude items. Forty items were generated from the data and are shown in Appendix 5. Table 9 summarises the attitude categories and the number (%) of attitude items for each of the six categories.

Table 9

Attitude items across attitude categories

Category	**Preliminary items**	**%**	**Finalised items**	**%**

1.	A palliative approach	19	47	18	50
2.	Physical Symptoms —Assessment and Management	3	8	3	8
3.	Family Support	4	10	4	11
4.	Social Care	7	18	6	17
5.	End of Life Care	5	13	3	8
6.	Professional Development and Reflection	2	5	2	6
Total Items		40	100	36	100

4.8.7 Refinement of attitude items

The process of review and item refinement by the researcher and supervision team resulted in the elimination of four attitude items. The following three attitude items were deleted as these were duplicated by skills items:

- I am able to provide comfort when a person is dying.
- People do not need to maintain their independence if they are receiving a palliative approach.
- I always encourage palliative care residents to eat even if they lack interest.

The following item was also a duplicate and was deleted.

- A positive attitude is helpful when providing a palliative approach.

A total of 36 attitude items were retained for inclusion in the developing instrument and for content evaluation in Phase 2 of the study (see Appendix 6).

4.9 Format of items

As well as being reliable and valid, a new instrument needs to be practical and

user friendly for respondents (DeVellis, 2012; Oppenheim, 2005). This includes making sure items are clear and unambiguous and words are selected with the educational and reading level of the target population in mind (DeVellis, 2012; Polit & Yang, 2016). Determining the format of the instrument to ensure its usability across the three themes of knowledge, skills and attitudes was based on two major considerations: first, that the paramount objective was to develop a standardised set of questionnaires that is easy to administer; and second, that the aim is provide an accurate assessment of the capabilities of nursing assistants to assist with professional development and training.

A closed-response approach provides a format that is relatively easy and quick for participants to answer and allows a greater number of questions to be asked within a given timeframe, yielding more information and providing a straightforward approach to scoring (Clark & Watson, 1995; Oppenheim, 2005; Schofield & Knauss, 2010). The advantages of closed, forced-choice questions in the context of the instrument's design objectives outweighed the advantages of open-ended questions, especially for when considering reliability and replicability.

4.9.1 Knowledge questions

A closed-response approach using the dichotomous variables True (T) and False (F), with the addition of a 'Don't Know'(DK) option, was selected for this study. A closed-response approach provides a format that is relatively easy and quick for participants to answer, and allows a greater number of questions to be asked within a given timeframe, yielding more information as well as providing

a straightforward approach to scoring (Clark & Watson, 1995; Oppenheim, 2005; Schofield & Knauss, 2010). Response formats for closed questions can include dichotomous yes/no response options, multiple-choice types with a number of response options (polytomous), and verbal and numerical rating scales. The closed-response dichotomous format also allows a straightforward comparison between the new instrument and the PCQN. The PCQN, discussed in section 2.4.1, is a 20-item quiz which uses dichotomous questions with the addition of the 'Don't know' option (Ross et al., 1996). It is suggested that a 'Don't Know' option differentiates between a lack of information and misinformation as this option can be used by respondents to indicate a lack of information, and reduce guessing (Courtenay & Weidemann, 1985; Pratt, Wilson, Benthin, & Schmall, 1992). As the PCQN is the comparison measure used to test convergence and divergence with the new instrument, a closed-response format using dichotomous responses with the addition of the 'Don't Know' option was adopted for the knowledge component

4.9.2 Skill statements

When instruments are used to probe more subjective information such as attitudes, opinions, beliefs, values, and perceived competencies, Likert scales are often used as a response format (DeVellis, 2012). They are also used when participants are required to indicate the frequency with which they do something, or, in the case of this study, if participants know how to perform a given skill or behaviour. For the skills items, a three-point scale was selected for participants to indicate: i) I do this every time I provide care, as necessary; ii) I

am unsure how; or iii) I do not know how to do this. Skill items were formatted as a list of independent statements grouped according to categories.

Response options for skills statements were modelled on options used by Giddens (2007) for determining what physical assessment skills nurses use and adapted for the Australian context by Birks, Cant, Ainsley, Chung, and Davis (2013).

4.9.3 Attitude statements

Attitude statements are amenable to the Likert scale format, in which the item is presented as a statement, also described as the stem, followed by a series of response options by which participants can indicate varying degrees of agreement or disagreement (DeVellis, 2012). The choice of response format in scaled responses can accommodate the extreme responses of emotional attitudes when statements are worded in a moderately strong way (DeVellis, 2012; Oppenheim, 2005); they can also provide few or extended response options which are clearly labelled. These categories can be converted into numerical codes for analysis (Schofield & Knauss, 2010).

In this study, a five-point Likert scale was selected for the attitude items, to capture differences of opinion related to the construct. The items were presented as a list of independent statements grouped according to category. Response options were provided as a five-point ordinal scale:

- Strongly Agree
- Agree

- Unsure
- Disagree
- Strongly Disagree

The five-point scale with a middle value allows more scope for ambivalence and delineation than an even-numbered scale (Lynn, 1986), which is important when examining attitudes.

4.10 Chapter Summary

This chapter has described the aim, data collection and methodology used to generate items in Phase 1 of this study and has discussed the significance of this phase to the instrument development process. A brief explanation of the stance taken on researcher reflexivity and rigour in the qualitative research process was provided. The chapter detailed the process of category development and item generation, and provided the results for each of the key attributes of knowledge, skills and attitudes. The results of final items following the process of review and refinement and the considerations related to the format of the items in the instrument were also presented.

Chapter 5 Phase 2: Content and Face Validation

5.1 Overview

The previous chapter detailed the process of item generation, review and refinement of each of the three key attributes of knowledge, skills and attitudes in Phase 1. This resulted in 51 knowledge items, 48 skills items and 36 attitudinal items ready for content and face validation in Phase 2. This chapter describes the aim, data collection method and results for three separate data collection processes used in Phase 2 to develop the instrument. The final section discusses the strengths and limitations of the content validation method.

5.2 Aim

The aim of Phase 2 was to validate the content of items generated in Phase 1 and to provide evidence of face validity. Establishing content validity is an essential requirement in instrument development and confirms that items are relevant and comprehensively cover the construct (DeVellis, 2012; DeVon et al., 2007; Lynn, 1986; Polit, 2015; Polit & Yang, 2016; Streiner & Norman, 2008). Content validation also assists in distinguishing items encompassing the construct of interest from other related constructs (Clark & Watson, 1995; DeVellis, 2012).

The goal of instrument development is to maximise validity even at the cost of reliability, which is why a co-efficient alpha of 0.70–0.80 is deemed acceptable as a measure of internal consistency, item homogeneity and correlation within a

new instrument intended for research purposes (DeVellis, 2012; DeVon et al., 2007; Nunnally & Bernstein, 1994). Face validity ensures the instrument looks as if it is measuring the relevant construct (Polit & Beck, 2017). In this study, items need to be relevant and reflect the type of palliative care provided by the whole of the target population (Clark & Watson, 1995).

5.3 **Method**

Following the generation and refinement of items outlined in Chapter 4, the next step taken to develop the instrument was to format the knowledge questions and skills and attitudinal statements in SurveyMonkey, an online platform used to build surveys, collect data and begin the steps to analysis. This tool was selected because it provides flexible question options to support rating scales, question ranking, open-ended and multiple-choice questions, demographic information, and provision for descriptive text (Massat, McKay, & Moses, 2009); it is therefore straightforward for the user to create surveys and to enter responses. In this study, participants were given the option of completing online, and entering their own responses.

Four separate surveys were created in SurveyMonkey. In the first instance, two knowledge surveys were created. One of these, Knowledge of a Palliative Approach, contained the 51 study-related knowledge items and was created to give participants the opportunity to 'get a feel' for the knowledge items before undertaking the validation process. This survey was optional. The three other

surveys, used for the validation process, are presented below in the order in which they were presented to participants:

1. Content Validation of Knowledge Questionnaire (CVKQ) which contained the 51 study-related knowledge items.
2. Content Validation of Skills Questionnaire (CVSQ) which contained the 48 study-related skills items.
3. Content Validation of Attitudes Questionnaire (CVAQ) which contained the 36 study-related attitudes items.

Each questionnaire opened with a participant information sheet, approved by the University Ethics Committee (approval number H9963) and agreement to participate, followed by seven demographic questions that covered gender, age, birthplace, level of education and the number of years worked in their role. Instructions for completing the content validation process for each of the three questionnaires were then detailed. Once participants agreed to proceed, they were transferred to the questionnaire's demographic questions and instructions explaining how to complete the validation process. 'The next section describes the Content Validation Index method used to validate content in Phase 2, followed by the sample selection and data collection.

5.3.1 Content Validation Index

A review by people who are knowledgeable about the content area, and an exposition of the content validation process, enables the confirmation of the construct (DeVellis, 2012; Polit & Yang, 2016). In this study, the Content Validity Index (Lynn, 1986) was chosen to validate item content and establish

clarity and relevance. Lynn introduced this rigorous method to the fields of nursing and health although an educational psychometrician is credited with developing it (Polit & Beck, 2006; Polit & Yang, 2016). Using this method, the content validity of individual items as well as the instrument's overall content validity may be calculated (Lynn, 1986; Polit & Beck, 2006; Polit & Yang, 2016).

Nursing experts in the field of aged care and palliative care were sought for participation in the validation processes. Recommendations to adopt a systematic approach to the recruitment, orientation and instruction of experts to the study and the validation processes were followed as outlined below (Grant & Davis, 1997; Lynn, 1986; Nunnally & Bernstein, 1994; Polit & Beck, 2017).

To compute the CVI value for items, a four-point ordinal scale was used, with 1 corresponding to an irrelevant item and 4 to a highly relevant item (Lynn, 1986; Polit & Beck, 2017). As recommended by Lynn (1986), items in this study were rated for clarity and relevance using the following scale:

1. not clear, not relevant;
2. not quite clear, not quite relevant (requires major revision);
3. clear, relevant (with minor revision);
4. very clear, very relevant.

5.4 **Data collection**

The survey method was chosen as the most efficient way to collect data from the experts. The approach was an iterative process with opportunities for

refinement of items specifying the construct.

5.4.1 Recruitment of experts

Experts who were research academics or directors of nursing (DONs) or care managers were contacted by email in the first instance, with the option of a phone call to discuss and clarify their participation in the study. Following responses either by email or by phone, an email invitation to participate was sent via Survey Monkey. DONs and care managers who agreed to participate were asked to extend an invitation to RNs and nursing assistants in their facilities to participate via a web link to the survey.

Four subgroups of experts were recruited as follows:

- Research academics in the field of palliative care and aged care (n=3) who had published in the field;
- Industry representatives (n=3) who held organisational responsibility for training and development of aged care staff, e.g. DONs or care managers;
- RNs supervising the direct care provided by nursing assistants in RACFs (n=3);
- Nursing assistants (n=3) with a Certificate IV in Aged Care and at least five years' experience in their role.

5.4.2 Defining the expert

The recruitment of experts in the field of aged care and palliative care was based on expert engagement and experience in the field, demonstrated by

qualifications, published works, or role and setting (Grant & Davis, 1997; Polit & Beck, 2017). Specifically, participants were deemed experts if they actively pursued research in the field of palliative care in aged care and therefore understood the construct and scope of a palliative approach; or they were industry representatives responsible for managing the training and development of nursing assistants; or they were RNs who supervised the care provided by nursing assistants in RACFs. In addition, nursing assistants themselves were deemed to be experts if they had at least five years' experience in their role. Selecting experts from within the target group is useful for ensuring that content is relevant and valid for that particular group (DeVellis, 2012; Polit & Yang, 2016).

5.4.3 Number of experts

How many experts are required to assess the content validity of instruments is not defined, and studies show variation in the number of experts consulted (Polit & Beck, 2006; Ugalde, 2009), usually ranging between three and twelve (Polit & Yang, 2016). Importantly, the number needed to establish content validity is determined by the application of the standard error of the proportion of the number of experts in agreement (Lynn, 1986). For instance, each item to be assessed as content valid must receive an endorsement of either 4 or 3 from the majority of content experts. If there are five or fewer raters, an item needs an endorsement of either a 4 or 3 by all raters—100% agreement— in order for it to be determined content valid (Lynn, 1986; Polit & Beck, 2017). When there are six or more experts, one or more can disagree.

Twelve experts were invited to participate in this study. This number was chosen to include three experts from each of the four groups of experts discussed above. Using different groups of experts from within the field provides a variety of expertise that strengthens the content validation process (Lynn, 1986; Polit & Yang, 2016; Tojib & Sugianto, 2006).

5.4.4 Instructions to experts

Experts were asked to comment on the format and user-friendliness of the instrument in addition to reviewing the item pool for clarity and relevance. Clarity of expression was of particular importance in this study as the population of nursing assistants is a culturally and linguistically diverse group with varying levels of education (Ford & McInerney, 2011; Mavromaras et al., 2017; Nochomovitz et al., 2010; Ronaldson et al., 2008).

5.4.5 Demographic variables

Across the four questionnaires, demographic data was collected to identify expert groups and to begin the process of defining the demographic variables required for subsequent iterations of the developing instrument. Questions for the content validation process were as follows:

- What is your gender?
- What is your age?
- Were you born in Australia?
- What is the highest level of education that you have completed?
- Please indicate where you work

- Please describe what you do
- How long have you been working in your role as indicated in the previous question?

A combination of drop-down answer options and open-ended responses was provided for participants' responses. An answer for each of the demographic questions was required before participants could progress to the next section.

5.4.6 Instructions for the validation process

Clear instructions describing what is involved in the validation process are essential (Polit & Beck, 2017). During the instrument development and design, the researcher addressed the factors which would enhance the comprehensibility of the new instrument for the target population. Experts were provided with clear instructions on how to rate items for clarity and relevance for each of the three questionnaires. They were asked to rate the clarity of items in an attempt to eliminate ambiguous terms and words, complex and difficult items, jargon and value-laden words, and negative and double negative phrases which can confuse participants (Clark & Watson, 1995; Nunnally & Bernstein, 1994; Polit & Beck, 2017; Rattray & Jones, 2007; Seyidova-Khoshknabi, Davis, & Walsh, 2011). Participants were invited to provide feedback on items by making comments and suggestions for overall improvement and were also asked to include content on important issues for nursing assistants that, in their opinion, was missing.

They were asked to comment on the design and format of the questionnaire as

well: was it user friendly, and how long did it take to complete? Finally, specific to the knowledge items, participants were asked whether the items, in their opinion, achieved a difficulty grading of one third easy items, one third moderately difficult items, and one third difficult items.

5.4.7 Item difficulty

The aim of applying a difficulty grading to the items in the development phase was to construct items capable of discriminating levels of knowledge, from low to high, within the target population of nursing assistants. A difficulty gradient prevents participants from being bored by easy items or frustrated by items that are overly difficult (DeMars, 2010). The difficulty grading outlined below was based on the researcher's assessment of items, using the following criteria outlined in Table 10.

Table 10
Item difficulty

Definition of term	Proficiency
Easy	• 'Commonsense' understanding/awareness • Content included in the educational unit within the Certificates in Aged Care *Deliver care service using a palliative approach*
Moderately difficult	• Content requiring foundation knowledge covered within units of the Certificates in Aged Care • Experience in role and setting of care
Difficult	• Content not included in educational unit *Deliver care service using a palliative approach* • Requires extensive experience in role and setting of care

While responses to this question were subjective, experts could comment if

they thought that knowledge items appeared to achieve the intended difficulty grading.

5.4.8 Expert follow-up

Of the twelve experts who were recruited to participate in the validation process, five did not initially complete the CVKQ. One follow-up email was sent via SurveyMonkey to these participants, explaining that the time frame for completion had been revised from 60 minutes to 30 minutes based on feedback from two participants. Following the email, four participants completed the CVKQ. One participant reported being unable to complete the CVKQ due to other commitments. Eleven participants completed the CVKQ.

A follow-up email was also sent to five participants about completing the CVSQ. Two of these participants declined to participate due to work commitments. Another follow-up email was sent two weeks apart to four and two participants respectively. One participant failed to respond by email and to a phone call, and did not complete the questionnaire. Nine participants completed the CVSQ.

A follow-up email was sent to six participants completing the CVAQ in the first instance, and a second follow-up to three participants three weeks later. One of these emails was recorded as bounced in SurveyMonkey's 'collect responses' option. As one expert was uncontactable, an additional expert based on the criteria outlined in section 5.4.2 was contacted to participate. Eleven of the original participants recruited to this phase of the study and one participant recruited as a replacement resulted in twelve participants completing the CVAQ.

The following sections outline the demographic data and sample characteristics of experts who completed the content validation of the three questionnaires CVKQ, CVSQ and CVAQ.

5.4.9 Sample characteristics

Eleven participants completed the CVKQ, a response rate of 92%. Seven participants were employed in an RACF, two were academics, one participant identified holding a conjoint appointment, and another identified working in aged care at an advanced practice level within a health authority. Of these participants, the majority (91%) were female; six were within the 45–54 age bracket and three within the 55–64 bracket. The majority (54.5%) were born in Australia. Six participants held tertiary-level qualifications, four held vocational-level qualifications, and one participant recorded Year 12 or equivalent as their highest level of education. Five participants had more than ten years' experience in their role.

Of the twelve participants invited to participate in the CVSQ, nine completed the online questionnaire, a response rate of 75%. Six of these participants were employed in an RACF and three were academics. The majority (78%) were Australian born, with one participant identifying the UK and another Sri Lanka as their country of birth. The majority of participants (78%) were within the 45–54 years age group, and seven of these (78%) had worked in their role for more than five years. A range of educational qualifications from Year 10 or equivalent to doctoral level was reported.

Twelve participants who were invited to participate in the CVAQ completed the

online survey, a response rate of 100%. The majority (87%) were female; eight were within the median age group of 45–4 years of age and five (42%) held a Master's-level qualification. Certificate III and IV in Aged Care were recorded by only one participant. Half the sample worked in a direct care role and the majority (67%) had more than five years' experience in their role.

Demographic data on the sample characteristics of experts is presented in Table 11.

Table 11

Demographic characteristics of experts completing the CVKQ , CVSQ and CVAQ

Variable		**CVKQ**	**CVSQ**	**CVAQ**
Sample size		11	9	12
Gender	Female	10	7	10
	Male	1	2	2
Age (Years)	18-24	-	-	-
	25-34	-	1	1
	35-44	2	1	2
	45-54	6	7	8
	55-64	3	-	1
	65-74	0	-	-
Country of	Australia	6	7	7
birth	UK	3	1	1
	Sri Lanka	1	1	1
	Samoa	1	-	-
	Missing			3
Highest level	PhD	2	2	3
of education	Masters	3	2	5
	Undergraduate	1	1	2
	Certificate IV Aged Care	3	-	1
	Certificate III Aged Care	-	-	1
	Diploma or Certificate (TAFE)	1	1	-
	Year 12 (HSC) or equivalent	1	1	-
	Year 10 or equivalent	-	2	-
Workplace	RACF	7	6	8
	Research Institute	2	3	4
	Other	2	-	-
Role	Manager/DON	2	2	2
	RN	3	1	3
	Nursing assistant	3	3	3

Variable		CVKQ	CVSQ	CVAQ
Role (cont.)	Academic	3	3	4
Length of time in role (years)	< 5years	4	2	4
	5-10 years	2	5	3
	>10 years	5	2	5

5.5 **Results**

5.5.1 Content validation of knowledge questionnaire

Each question in the CVKQ was scored by the experts for clarity and relevance based on the Likert scale. The following item (Question 1) in Table 12 provides an example of the content validation process. The results of the content validation of knowledge questions and revision of questions based on expert comments are shown in Appendix 7.

Table 12

Validation of Knowledge Questionnaire

Question **(and correct answer)**	Original questions	Expert comments	Revised questions	CVI Clarity **4 very clear 3 clear with minor revision 2 clear with major revision 1 not clear**	CVI Relevance **4 very relevant 3 relevant with minor revision 2 relevant with major revision 1 not relevant**
Question 1 TRUE	Palliative care aims to improve the quality of life for people with life-limiting conditions.	1. Explain life-limiting in simple language	A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.	4= 91% (n=10) 2=9% (n=1)	4=100% (n=11)

5.5.1.1 Retention and deletion of knowledge questions

The decision to retain questions that achieved a score for relevance of 100% was based on the rationale that all were rated either very relevant (4) or relevant with minor revision (3), indicating appropriate content validity using the CVI method (Lynn, 1986; Polit & Beck, 2017). In addition to establishing content validity, another important consideration was to produce a final instrument for use in the practice setting; it was therefore decided that reducing knowledge questions to approximately 20 for the final instrument could be achieved with a strict cut-off of 100% relevance in the first round of content validation.

Items with 100% relevance, rated either 4 (very relevant) or 3 (relevant with minor revision) by the experts, were retained. All items rated below 4 or 3 were removed. Where experts made suggestions or comments for improvement for items rated as '3', these items were amended.

Eighteen knowledge questions were deleted as they did not achieve the 100% relevance of the CVI method for content validity. These items can be seen in Appendix 7.

5.5.1.2 New questions

As requested, experts provided feedback on content that had not been included and on whether the questions were deemed to be easy, moderately difficult or difficult. New questions were generated based on this feedback and designated as either easy, moderately difficult, or difficult based on the definitions outlined

in section 5.4.7. Table 13 provides the new questions generated from expert feedback.

Table 13

New knowledge questions

New Questions	**Feedback**
52. Encouraging family to be involved in care is an important part of a palliative approach. TRUE/Easy	I have answered questions so you can also see if any don't match what you thought—I also feel questions around other symptoms would be good, e.g. 1. encouraging family to be involved in care is an essential part of a palliative approach (Yes)
53. Shortness of breath is not a problem when a person is dying. FALSE/Difficult	2. shortness of breath is acceptable when someone is dying (No)
54. Bladder and bowel problems can cause discomfort when a person approaches the end of life. TRUE/Moderately difficult	3. bladder and bowel problems are common areas that can cause discomfort as a person reaches end of life (Yes)
55. Dehydration is a problem when a person is close to death. FALSE/Difficult	4. natural dehydration has positive benefits when someone is actively dying (Yes)
56. It is important to debrief with colleagues and share experiences when providing a palliative approach. TRUE/Moderately difficult	It is important to debrief with colleagues, and share experiences, for your own wellbeing. – thanks for opportunity to comment

The following comments and suggestions from experts, shown in Table 14 below, were considered to belong with the attitudinal and skills statements and were transferred to those categories.

Table 14

New attitudinal and skills statements

Attitudinal Statements	1. Effect of cultural values, beliefs and attitudes of staff 2. Staff stress and anxiety looking after dying 3. It's best to leave any care delivery to staff when a person is dying (No) 4. What about staff coping
Skills Statements	The ability to respond to families when a relative is dying is very difficult for nursing assistants. I wonder whether adding a few statements about appropriate responses from nursing assistants [would help]?

5.5.1.3 Review of knowledge difficulty

A review of the difficulty grading of knowledge questions was undertaken to determine if a balance of easy, moderately difficult and difficult questions was achieved following deletion of questions, the transfer of questions to the CVAQ, and the inclusion of four new questions. Questions were rewritten to provide balance across the difficulty grades.

Based on the difficulty index discussed in section 5.4.7., there appeared to be a balance of easy, moderately difficult and difficult questions:

- Easy questions (n=11)are shown in Appendix 6 marked E.
- Moderately difficult questions (n=9)are shown in Appendix 6 marked MD.
- Difficult questions (n=13)are shown in Appendix 6 marked D.

Feedback based on experts' subjective opinions generally endorsed each question's difficulty, as indicated in Table 15.

Table 15

Expert feedback on difficulty of knowledge questions

Question	Comment
Please rate whether you thought the items achieved a difficulty grading of one third easy, one third moderately difficult and one third difficult	Some ambiguous questions that for a care worker may be confusing. I have already given my opinion to individual questions. Overall, I think most questions are relevant but need to be simplified. We have [a] lot of CALD staff who may not understand 'difficult' words. I think that aiming at the AIN level of employee most of the questions were at a good level.
Yes, difficulty grading achieved	(n=7) 67%
Not quite, needed easier questions	(n=1) 9%
Not quite, needed more moderately difficult questions	(n=1) 9%
Not quite, needed more difficult questions	(n=2) 18%

5.5.1.4 Summary

Thirty-three knowledge questions achieved 100% relevance and were retained. Of these, three were removed from 'knowledge' and placed with the attitudinal statements. Four new questions were generated from expert feedback. The majority of questions were amended to improve clarity, necessitating a review of all items in a second round of expert validation. Before this happened, the thirty-four knowledge questions were formatted in SurveyMonkey in a questionnaire entitled 'Face Validation of Knowledge Questions' for face

validation by nursing assistants. Of the 34 questions, 25 were True responses and 9 were False.

5.5.2 Strategies to improve clarity

As only nine of the eleven experts rated the instructions 4 or 3 for clarity (81%), assistance was sought on one occasion from the Professional Communication Academic Literacy Support service to improve clarity, offered by the School of Nursing and Midwifery at the researcher's university. After feedback from this service, the instructions in all three questionnaires were revised. The changes made to the instructions to the CVKQ are shown in Table 16.

Table 16

Changes to instructions

From	To
Instructions for competing questionnaire The purpose of this questionnaire is to learn about your knowledge of palliative care. Another term for palliative care is a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. 1. Please respond to each statement True, False or Don't Know 2. Please respond to ALL questions	**Instructions for competing questionnaire** The purpose of these questions is to learn about your knowledge of a palliative approach. All questions concern the care of a person receiving a palliative approach and his/her family in the place where you provide care. **Instructions for completing the questionnaire** 1. Please answer each question True, False or Don't Know 2. Please answer ALL questions

5.5.3 Content validation of skills statements

The Content Validation of Skills Questionnaire (CVSQ) was the second questionnaire to be presented to the experts for review. Each statement in it was assigned a score by the experts for clarity and relevance based on the Likert scale. Statement 1 in Table 17 provides an example of the content validation process for skills statements. The scores for clarity and relevance for all statements, as well as expert comments and revisions of statements, are shown in Appendix 7.

Table 17

Content validations of skills questionnaire

Item	**Original item**	**Expert comments**	**Revised items**	**CVI Clarity** 4 very clear 3 clear with minor revision) 2 clear with major revision 1 not clear	**CVI Relevance** 4 very relevant 3 relevant with minor revision 2 relevant with major revision 1 not relevant
Statement 1	I observe what an individual can do independently.	Will depend on what the observation is and the level of the worker.	Item to remain as is	4=89% (n=8) 2=11% (n=1)	4=89% (n=8) 3=11 (n=1)

5.5.3.1 Retention of skills statements

Following the decision to retain items with a relevance score of 100%, all statements rated either 4 (very relevant) or 3 (relevant with minor revision) by the experts were retained. All statements rated below 3 were excluded. Where experts made suggestions or comments for improving statements rated 3, the statements were amended where possible. Thirty-nine of the 48 skills statements achieved a CVI of 100% relevance. The other nine were deleted as they did not achieve a score of 100% relevance. These are shown in Appendix 7.

In all, twenty-two statements were amended based on feedback and a rating of less than 4 for clarity. Statements were then formatted in SurveyMonkey in a questionnaire entitled 'Face Validation of Skills' for the second process of validation by a sample of nursing assistants (n=3).

5.5.4 Content validation of attitudinal statements

The Content Validation of Attitudes Questionnaire (CVAQ) was the third questionnaire to be presented to the experts for review. Each item in the CVAQ was assigned a score by the experts for clarity and relevance, based on the Likert scale. The following item (Statement 1) in Table 18 provides an example of the content validation process for attitude items. Appendix 7 provides the scores for clarity and relevance for all statements, as well as expert comments and revisions of statements.

Table 18

Content validation of attitudes questionnaire

Original statement	**Expert comments**	**Revised statements**	**CVI Clarity** 4 very clear 3 clear with minor revision 2 clear with major revision 1 not clear	**CVI Relevance** 4 very relevant 3 relevant with minor revision 2 relevant with major revision 1 not relevant
Instructions for completing the questionnaire The purpose of these statements is to learn how nursing assistants feel providing a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. • Please indicate how much you agree or disagree with each of the following statements. • Please respond to ALL statements.	Maybe shorten the second sentence	The purpose of these statements is to learn how nursing assistants feel providing a palliative approach. All statements concern the care of an individual **receiving a palliative approach** and his/her family in the place where you provide care. **Instructions for completing the questionnaire** • Please indicate how much you agree or disagree with each of the following statements. • Please respond to ALL statements.	4= 92% (n=11) 3=8% (n=1)	-
Statement 1 A palliative approach can help improve a person's quality of life.	As long as they know what QoL is	A palliative approach can help a person's quality of life (no change).	4=92% (n=11) 3=8.3% (n=1)	4=92% (n=11) 3=8.3% (n=1)

5.5.4.1 Retention of attitude statements and new attitude statements

Statements were retained if they achieved a CVI of either 4 (very relevant) or 3 (relevant with minor revision), indicating endorsement of 100% relevance by the experts. As requested, experts provided feedback on content that had not been included. Three new statements were generated following their suggestions. These are shown in Table 19.

Table 19

New attitude statements

Question	**Response**	**Comment**	**New items**
Is there any other content relevant to the attitudes of nursing assistants that you think should be included in this questionnaire?	No=83.3% (n=10) Yes=16.7% (n=2)	Possibly around what training they have received and if they believe it needs to be a priority—I feel comfortable when a resident decides they do not want any more treatment and are saying they are ready to die? I find it hard when a person stops eating and drinking for days before they actually die? Family should be involved as much as possible in caring for a person with a palliative approach.	1. Training in a palliative approach is a priority for my role. 2. I feel comfortable when an individual receiving a palliative approach says that they are ready to die. 3. I find it hard when a person stops eating and drinking in the days before they die.

Nineteen statements were deleted following the CVI process as these items did not achieve endorsement of either 4 or 3 by the experts. These items are shown in Appendix 7.

5.5.4.2 Summary

Twenty-one attitude statements received a CVI for relevance of 100%. Six of the 21 were amended based on expert feedback. Nineteen items were deleted. The 21 retained statements were formatted in SurveyMonkey for the face validation process with a sample of nursing assistants (n=3).

5.6 Face validation

Face validation has been defined as the layperson's acceptance that items are sound, clear and relevant, look like they are measuring the right attribute and represent the purpose of the instrument, and are presented and formatted acceptably (Del Greco, Walop, & McCarthy, 1987; Lynn, 1986; Polit & Yang, 2016; Streiner & Norman, 2008). Face validation was conducted separately after the content validation process and aimed to evaluate if the items were clear and comprehensible to a sample of the target population (n=3).

5.6.1 Method

The method used to review the face validity of items was the CVI, with the difference being that all items would need to achieve 100% clarity (4 = very clear/ 3= clear with minor revision) to be retained for a second round of validation by experts. Participants were asked to rate each item on a four-point Likert scale, and were given the opportunity to suggest improvements to

individual items.

5.6.2 Recruitment and sample

Three nursing assistants were recruited from one of the RACFs that had participated in the content validation process. The only inclusion criterion was that the nursing assistants worked in the facility. There was no requirement for length of experience in role, or of educational qualifications.

5.6.3 Demographic characteristics

Table 20 shows the demographic characteristics of the nursing assistants who undertook the face validation of the knowledge, skills and attitudes questionnaires. Of the nine participants who completed the process, the majority were female. The greatest number of participants were within the 24–35 age group, with India and Bangladesh recorded as the country of birth for most. Two participants held tertiary-level qualifications and six held vocational-level qualifications. One participant reported Year 12 or equivalent as their highest level of education.

Table 20

Demographic characteristics of nursing assistants in face validation process

Variable		**N**
Gender	Female	7
	Male	2
Age	25-34	4
	35-44	2
	45-54	1
	55-64	2
Country of birth	Bangladesh	2
	Fiji	1
	India	4
	Kenya	1
	missing	1
Highest level of education	Masters	1
	Undergraduate	1
	Certificate IV Aged Care Certificate III	3
	Aged Care	1
	Diploma or Certificate (TAFE)	2
	Year 12 (HSC) or equivalent	1
Length of time in role	<5 years	3
	5-10 years	3
	>10 years	3

5.6.4 Results

Thirty-four knowledge items were evaluated by the nursing assistants. Of these, 33 items achieved 100% clarity (4 or 3) and were retained. Two questions with a CVI 3 for clarity were re-written. These were:

- Question 12

  When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.

- Question 21

  A dry mouth is one of the most common symptoms in a person who is no longer eating or drinking.

Aiming for maximum clarity in the face validation process, one item did not achieve a CVI of 100% and was deleted:

- Question 13

  The age group of people requiring a palliative approach is getting younger.

On review of two items (29, 30), they were deemed to be assessing skills and attitudes:

- Question 29

  A palliative approach requires developing the skill of self-reflection.

This item was moved to the Content Validation of Skills Questionnaire (CVSQ) for a second round of content validation.

- Question 30

  In a palliative approach professional development is not necessary when care providers can learn on the job.

This item was moved to the Content Validation of Attitudes Questionnaire (CVAQ) for a second round of content validation.

A total of 31 knowledge items proceeded to a second round of content validation by experts. Thirty-nine skills items were evaluated by nursing

assistants and all achieved 100% for clarity. Three items were rated with a CVI 3. The following two were re-written, but one was retained as is.[2] No items were deleted.

- Statement 2

  I provide care based on a person's care plan.

- Statement 3:

  I assist with updating care plans.

A total of 39 final skills items proceeded to a second round of content validation by experts.

Twenty-one attitude items were evaluated by nursing assistants and all achieved 100% (rated either 4 or 3) for clarity. Two were rated with a CVI 3 and were re-written, as shown below. As the instructions also received a 3 for clarity (requiring minor revision), the advice sought from the Professional Communication Academic Literacy Support outlined in section 5.5.2 was used to improve clarity.

- Item 1

  A palliative approach can improve a person's quality of life.

- Item 12

  I feel comfortable when a person receiving a palliative approach says that they are ready to die.

[2] Statement 21: I direct families to other members of the care team when they need further advice.

In all, twenty-one attitude items were evaluated by nursing assistants. Nineteen achieved 100% clarity (4 or 3) and were retained. Two items with a CVI 3 for clarity were re-written.

Two items were deleted following the CVI process as they did not achieve endorsement of either 4 or 3 by participants:

- Item 3

  I help improve the quality of care when a person is dying.
- Item 13

  I find it hard when a person stops eating and drinking in the days before they die.

A total of 19 attitude items proceeded for a second round of content validation by experts.

5.7 **Second round content validation**

The aim of the second round of content validation was to present all items from the three questionnaires on knowledge, skills and attitudes to the experts for a second look. The majority of items had been revised in the first round based on expert feedback and after passing the face validation stage.

The CVI was used for the second content validation. This time, each item needed to achieve 100% for both relevance and clarity—endorsement with either a 4 or 3 by all experts—for it to be retained. No further amendments to the item could be undertaken.

5.7.1 Data collection

A survey containing all the retained, amended items from the first round was formatted in SurveyMonkey entitled ‘Content Validation 2 (CV2)’. Ten of the 12 original participants invited to participate in the second round validation process completed the CV2, a response rate of 83%. All participants were female, with the majority (60%) within the 45–54 age group. Seven participants identified Australia as their country of birth. Seven held tertiary-level qualifications; three held vocational-level qualifications. The majority (60%) worked in an RACF, and four of these participants worked in a direct care role. Six participants had been in their role for more than five years (Table 21).

Table 21

Demographic characteristics of experts in second round content validation

Variable		**N**
Gender	Female	10
	Male	-
Age	18-24	-
	25-34	-
	35-44	2
	45-54	6
	55-64	1
	65-74	1
Country of birth	Australia	7
	UK	1
	Sri Lanka	1
	New Zealand	1
Highest level of education	PhD	2
	Masters	5
	Undergraduate	-
	Certificate IV Aged Care	1
	Certificate III Aged Care	2
	Diploma or Certificate (TAFE)	-
Workplace	RACF	6
	Research Institute	3
	Other	1
Length of time in role	< 5years	4
	5-10 years	3
	>10 years	3

5.7.2 Results of second round content validation

Of the 31 knowledge items evaluated by experts, three items did not achieve

100% (rated either 4 or 3) for clarity and relevance. These items were deleted and are shown in Appendix 7 as CV(2). Of the 39 skills items, item 9 did not achieve 100% for clarity and relevance and was deleted – see Appendix 7. Of the 19 attitude items, all items achieved 100% for clarity and relevance, and were retained.

Based on the criteria for item difficulty discussed earlier (section 5.4.7), six of the retained knowledge items were deemed to be easy, 14 moderately difficult, and eight difficult. The Knowledge Questionnaire contained 22 True responses and six False responses.

5.7.3 Content validity for total instrument

In addition to computing the content validity of individual items for relevance and clarity based on a rating of either 4 or 3 by participating experts, the instrument's overall content validity was determined. Two methods can be used to compute the overall CVI, also known as the scale content validity or S-CVI (Polit & Beck, 2006, 2017; Polit & Yang, 2016). The first and preferred method works out the average item CVI, which involves summing all items rated either 4 or 3 and dividing by the number of items. Using this method to compute the value for the instrument's CVI or S-CVI following the second round content validation process, an overall score of 0.96 (85/89) was attained for the instrument.

The second method, termed the I-CVI universal, requires all experts to have rated each item 4 or 3. It is noted that as the number of experts increases, the likelihood of attaining total agreement is reduced, so this method is regarded as

a conservative approach to determining the content validity of an instrument (Polit & Beck, 2006). In this instrument, 85 of 89 items were scored 4 or 3 by all experts (1.0 x85 +.80+.90+.90+.90) = 88.5/89), returning a value of 0.99 for the instrument's CVI or S-CVI.

In the final analysis, following the second round of content validation, only one item failed a rating of 4 or 3 for relevance of content.[3] Therefore, when relevance alone is calculated, the value for the S-CVI average is .99 (88/89) and the universal agreement value is higher, at 99.7 (88 + .80 = 88.8/89). Both methods indicate that the overall content validity for the instrument at this stage of its development is above .90, with 100% agreement on individual items (rated 4 or 3), well above the recommended .78 agreement. These values are evidence of excellent content validity for the developing instrument (Polit & Beck, 2017).

5.8 **Strengths and Limitations of the CVI method**

This study adheres to the two-stage process outlined by Lynn (1986): the development process conducted in Phase 1 to generate items reported in chapter 4, and the judgement-quantification process reported in Phase 2, in this chapter. The quantification component of this second phase of the study using the CVI method is based on responses provided by experts to establish the content validity of items for the developing instrument.

The strength of the CVI as a method of content validation is its flexibility and

[3] Knowledge item number 8; see Appendix 6

practicality in terms of time and cost: it is relatively time-efficient and easy to complete, and requires a minimum of three experts (Lynn, 1986; Polit & Beck, 2017; Tojib & Sugianto, 2006). It also provides data from experts at both the individual item and overall instrument level (Polit & Beck, 2017; Polit, Beck, & Owen, 2007). It is a frequently used method because of these factors.

Limitations and criticisms of the CVI as a method include a lack of adjustment for chance agreement, which may inflate values for items (Polit & Beck, 2006; Tojib & Sugianto, 2006). This is especially the case with five or fewer raters, which prompted Lynn to develop criteria that take into account chance agreement by incorporating the standard error of proportion. While increasing the number of experts allows some disagreement on individual items, it also decreases the likelihood of total agreement; however, as demonstrated in the previous section 5.7.3. content validation for the total instrument exceeded the acceptable limit of 0.78. In this study, a cut-off of 100% (a score of 4 or 3) by all experts for item relevance and clarity was required for items to proceed beyond the second round content validation. Ten experts completed the second round of content validation, limiting chance agreement among raters.

It has been pointed out that the multipoint ordinal scale is, in effect, collapsed into two points, or dichotomies: relevance or irrelevance; which has the effect of 'throwing away' information (Polit & Beck, 2006; Polit & Yang, 2016). To overcome this problem, experts were asked to comment on items or make suggestions for improvement; this provided maximum information about items and informed revisions (Polit & Yang, 2016).

It has also been pointed out that the CVI on its own does not reveal whether an instrument comprehensively captures the construct of interest (Tojib & Sugianto, 2006). To combat this limitation, experts were asked to identify content that they believed should be included, allowing the opportunity to integrate new qualitative data into the process (Polit & Beck, 2017). As well as strengthening the content validation process, drawing different types of data together around the substantive topic is an important element of integration in a mixed methods design (Bazeley, 2013).

5.9 **Chapter summary**

This chapter has discussed the aim of Phase 2 of this study, which was to validate the content of the developing instrument using CVI. This method uses experts to rate the relevance and clarity of items for a new instrument. The sample and recruitment of experts was described, as were the results for each of the three content areas of knowledge, skills and attitudes rated by the experts. Following a second round of content validation for revised items, a final pool of 85 items was established for pilot testing in Phase 3, consisting of 28 knowledge, 38 skills, and 19 attitude items. Content validation of the new instrument (S-CVI) following the second round validation involved using two methods to evaluate the total instrument. First, the average of all items rated either 4 or 3 were summed to produce an overall score for content validity of 0.96, and then the S-CVI universal method, which requires agreement by all experts, was applied. Of the 89 items, 85 were so endorsed, giving an overall score for the instrument's content validity of 0.99. These results endorsed the

progress of the developing instrument, ready for the pilot test described in the next chapter.

Chapter 6 Phase 3: Pilot test

6.1 Overview

Phase 3 of this study evaluates the usability of the instrument in the setting where it will be used, and examines the performance capabilities of the new instrument in evaluating the knowledge, skills and attitudes in a sample of nursing assistants. The aim and purpose of Phase 3 are discussed followed by the sample, setting and data collection procedures, outlining the two modes of data collection. The results of the pilot test showing the usability and discriminative properties of the instrument are presented.

6.1.1 Aim

The aim of Phase 3 was twofold: to test the overall usability of the instrument in both online and paper format with a sample of nursing assistants, and to assess the performance capabilities of the instrument in discriminating knowledge, skills and attitudes between groups of nursing assistants, based on their years of experience.

6.1.2 Pilot testing

Pilot testing, or pretesting a new instrument, is an essential step before using it in a major study (DeVellis, 2012; Leon, Davis, & Kraemer, 2011; Oppenheim, 2005; Pett, Lackey, & Sullivan, 2003; Polit & Yang, 2016). Pilot testing is conducted to evaluate every aspect of the instrument, including instructions, the format of items and response options, and how these are assessed. Any problems with the administration of the instrument, its overall acceptability

and burden on respondents, as well as whether items are being answered in the way expected, can be identified before it is put into service: a pilot study tests the feasibility of the method and study procedures to be used in the larger scale test, and can be used to determine any modifications that may be required (Conn, Algase, Rawl, Zerwic, & Wyman, 2010; Leon et al., 2011).

6.2 Method

6.2.1 Sample and setting

As the pilot study is intended to test the overall usability of the instrument, its reliability and validity are not tested in this phase (Onwuegbuzie et al., 2010; Polit & Yang, 2016). For this reason, the sample of participants recruited was in keeping with the recommendation that, when the purpose is preliminary instrument development, the sample size be at least one-tenth the size of the proposed larger-scale study with a minimum sample of 30 participants and approximately twelve participants per group when there are two or three groups (Johanson & Brooks, 2010; Pett et al., 2003).

To test the overall usability of the developing instrument and to assess the potential for discrimination between groups of nursing assistants, a purposive sample of nursing assistants (n=61) from two RACFs was recruited. Considerations focused on purposive sampling of the target population in the setting in which the final instrument will be used, and the participants were intended to comprise equal numbers in three groups at two sites. As for the setting, both sites A and B provided low-care and high-care places, matching the criteria for the field study and ensuring that nursing assistants would be

exposed to high-care residents who warranted the application of a palliative approach.

Site A was the larger of the two sites and part of a community-based organisation. Site B was a private incorporated body (Australian Government Department of Social Services, 2014). Both sites reflect the overall setting of residential aged care in Australia, with a large representation of private organisations and smaller representation of community-based organisations.

6.2.2 Inclusion criteria

Three groups of ten nursing assistant participants were invited to participate from both sites A and B:

- Group 1: less than or equal to two years' experience in role (n=10)
- Group 2: between two and five years' experience in role (n=10)
- Group 3: more than five years' experience in role (n=10)

Based on these criteria, all nursing assistants from the participating sites were eligible to participate.

6.2.3 Recruitment

Recruitment at site A was initiated through phone calls and emails to the facility in the lead-up to the pilot study. Initial contact involved a discussion about this phase of the study with the facility manager, who was sent the participant information sheet (Appendix 3) following an indication of interest in the study. A follow-up phone call established that the site was still willing and able to

participate in the pilot testing of the instrument, although a new care manager had been appointed in this time.

Recruitment at Site B commenced after completion of data collection at Site A. The DON expressed interest in participating in the study after a preliminary phone call in which the researcher introduced herself and the purpose of the study. On receipt of the participant information sheet and agreement for the site to participate, a request was made to the research unit at the researcher's university to amend the existing ethics protocol[4] to include site B.

The educator of the facility at Site A and the DON at site B facilitated data collection and distributed flyers to interested staff. The flyer is presented in Appendix 2.

6.3 Data collection

6.3.1 Mode of administration

Different modes of administration using online and paper-based surveys were considered to maximise the response rates in this population. A mixed mode of administration has been found to maximise response rates in an educated, computer-literate study population (Greenlaw & Brown-Welty, 2009). One of the advantages of online survey administration is the reduction in data error caused by the inputting of responses from paper-based surveys (Greenlaw & Brown-Welty, 2009), although online responses achieve lower response rates

[4] Initial approval provided for Site A only

(33%) than those administered on paper (56%) (Nulty, 2008). This may be because of access to technology, or lack of familiarity with online surveys. The preference for a paper format was anticipated for the study population in RACFs based on these findings. Study participants were offered the choice of completing the survey in paper format, which would counter any bias with accessing technology, or a lack of familiarity with or resistance to completing an online survey, as well as being able to complete online if preferred. If sufficient numbers participated in each mode, validation of the instrument for both online and paper formats could be achieved.

6.3.2 Format of instrument

Following the finalisation of items in Phase 2, the three questionnaires were formatted as one instrument in SurveyMonkey for pilot testing. The paper copy was derived from a PDF of the formatted online instrument. Minor adjustments to spacing were made to the paper-based version, but an effort was made to ensure that both versions appeared the same. The ordering of the three separate instruments, the instructions, font and point size, were formatted identically in both modes to ensure consistency across formats.

The order of the separate questionnaires in the instrument was:

1. PANA_Knowledge Questionnaire

This contained the revised instructions on how to complete the questionnaire, along with the 28 finalised knowledge items. The PANA_Knowledge Questionnaire was formatted with 'True', 'False', 'Don't Know' response options.

Each correct score was assigned a score of one, and each incorrect or 'don't know' response scored zero.

2. PANA_Skills Questionnaire

This contained the revised instructions on how to complete the questionnaire along with 38 skill items. Participants were asked to select an option that best described their ability. The response format at site A was:

- I do this every time I provide care, as necessary
- I do not know how to do this
- I am unsure how to do this

After the pilot at site A, changes were made to these response options discussed in section 6.4.9.

3. PANA_Attitudes Questionnaire.

This contained the revised instructions on how to complete the questionnaire along with 19 attitude items. This questionnaire used a 5-point Likert scale and asked participants to indicate how much they agreed or disagreed with the items. The response options were: strongly agree, agree, unsure, disagree, and strongly disagree.

6.3.3 Participant information

Participant information explained the purpose of the study, stressed its voluntary and confidential nature, and indicated an estimate of the time needed to complete the instrument (see Appendix 3). The estimated time to complete

the instrument was indicated to be the same for both modes of administration. Consent was implicit when participants indicated their agreement to proceed following the participant information. Participants were then asked to complete six demographic questions first, including their date of birth and their initials: these were to identify participants who attempted both modes, and to pilot the process for identifying participants for the test-retest sample required in Phase 4. In the event that a participant completed the instrument online as well as on paper, a decision was made to accept the first completed mode for use in the results.

6.3.4 Usability of instrument

Each questionnaire was followed by a series of questions on the usability of the questionnaire. The questions were:

- Was the questionnaire easy to complete?
- Were the questions/statements clear and easy to understand?
- Did the questions/statements flow logically?
- How long did the questionnaire take you to complete?
- Do you think the questions were a mix of easy, moderately difficult and difficult questions? (Knowledge instrument only)
- Were the answer options adequate? (Skills and Attitudes instrument only)
- Are there any other comments or suggestions you would like to make?

6.3.5 Online survey.

The online survey was entitled 'Pilot PANA_Knowledge, Skills & Attitudes Questionnaires'. The link to the online version of the instrument was included in the flyers provided to the participating sites, and was also sent to the responsible person at both sites A and B. The fliers were also used to advertise the study to the facility staff (Appendix 2).

6.3.6 Instrument booklet

Thirty paper copies of all information and all three questionnaires were formatted into an instrument booklet to reflect the online survey and, along with a collection box, were delivered to site A. To ensure participant confidentiality, separate survey administration instructions and an individual envelope stamped 'Confidential' were provided for each paper copy prior to pilot testing at site B (see Appendix 8).

6.4 Results

The results of the demographic data from this pilot study are presented in Table 22. Ninety-seven per cent of participants (n=27) recruited at Site A were female. The mean age for Group 1 (those with less than two years' experience) was 36 (range 19–52). Sixty per cent of this group was Australian born and had completed either Certificate III or IV in Aged Care. Four participants indicated Year 10 as their highest level of education. In Group 2 (between two and five years' experience), the mean age was 45 years (range 32–57). Of this group, 80% were Australian born and 50% had completed Certificate III or IV in Aged

Care. One participant had completed an undergraduate degree, the highest level of education noted, and three participants indicated Year 10 and one participant indicated Year 12 as their highest level of education. The mean age in Group 3 was 55 years (range 30–66); 70% indicated they were Australian born. Eighty per cent of these participants (n=8) held Certificate III or IV in Aged Care as their highest level of education. Two participants indicated Year 10 and Year 12 as their highest level of education.

Of the nursing assistant participants (n=31) recruited at Site B, 97% (n=30) were female. The mean age for Group 1 (n=2) was 28 (range 18–39). Both participants in this group were born in Australia; one held Certificate III in Aged Care and the other participant indicated a Diploma or Certificate as the highest level of education. For group 2 (n=7), the mean age was 43 (range 39–50 (missing value -1), with 42% of this group Australian born. Certificate III or IV in Aged Care was held by all participants.

For group 3 (n=22) the mean age was 50 (range 37–62), with 36% indicating they were Australian born. Seventy-seven per cent of these participants (n=17) held Certificate III or IV in Aged Care as their highest level of education. Three participants indicated Year 10 and Year 12 as their highest level, two participants held a Bachelor's degree and one a postgraduate degree.

While the numbers for the pilot study were almost the same across the two sites, site B did not have equal groups, and the majority of participants were those with more than five years' experience. Only two participants had less than two years' experience. The second pilot shows that participants were slightly

younger than participants at Site A. In total, 44 of the 61 participants (72%) held either Certificate III or Certificate IV in Aged Care.

Table 22

Demographic characteristics Phase 3 pilot test

Groups at Site A	**Gender**	**Age Mean**	**Years Range**	**Australian-born**	**Education**
Group 1 (n=10)	Female 100%	36	19-52	60%	Year 10 or equivalent (n=4) Cert. 3 Aged Care (n=3) Cert. 4 Aged Care (n=3)
Group 2 (n=10)	Female 100%	45	32-57	80%	Year 10 or equivalent (n=3) Year 12 or equivalent (n=1) Cert. 3 Aged Care (n=4) Cert. 4 Aged Care (n=1) Undergraduate nursing (n=1)
Group 3 (n=10)	Female 90% Male 10%	55	30-66	70%	Year 10 or equivalent (n=1) Year 12 or equivalent (n=1) Cert. 3 Aged Care (n=2) Cert. 4 Aged Care (n=6)
Total (N=30)	–	45.3	19-66	–	
Groups at site B					
Group 1 (n=2)	Female =100%	28.5	18-39	100%	Cert. 3 Aged Care (n=1) Diploma or Certificate TAFE (n=1)
Group 2 (n=7)	Female =85.7% Male = 14.2%	42.6	39-50*	42%	Cert. 3 Aged Care (n=6) Cert. 4 Aged Care (n=1) Diploma or Certificate (TAFE)
Group 3 (n=22)	Female = 100%	49.6	37-62	36%	Year 10 or equivalent (n=2) Year 12 or equivalent (n=1) Cert. 3 Aged Care (n=9) Cert. 4 Aged Care (n=8) Bachelor degree (n=2) Postgraduate degree (n=1)
Total (N=31)	–	40.1	18-62	–	

Note: * +1missing value

6.4.1 Online responses

Ten participants (16%) completed the pilot study online: four from site A (13%) and six (19%) from site B. All other participants completed the paper-based instrument. Responses from the paper surveys were entered into SurveyMonkey by the researcher to begin the process of analysis.

6.4.2 Usability of PANA_Knowledge Questionnaire

A basic analysis using the results generated by SurveyMonkey indicated good overall usability of the instrument across the two sites. In the PANA_Knowledge Questionnaire, 97% of participants from Site A and 94% from Site B indicated that the questionnaire was easy to complete, 90% and 97% indicated that the questions were clear and easy to understand, 97% and 100% indicated the questions had a logical flow and 90% and 87% indicated that they found the knowledge questions to be a mix of easy, moderately difficult and difficult. The majority of participants at site A (n=22) and site B (n=18) indicated that the questionnaire took between five and ten minutes to complete. All results and comments are shown in Appendix 8.

6.4.3 Usability of PANA_Skills Questionnaire

In the PANA_Skills Questionnaire, 100% of the participants from Site A and 94% from Site B indicated that the questionnaire was easy to complete, 100% of participants at both sites indicated that the questions were clear and easy to understand, and 97% and 100% indicated the questions had a logical flow. The majority of participants from site A (n=24) and site B (n=26) indicated that the

questionnaire took between five and ten minutes to complete; however, only 79% (n=23) of participants from site A indicated that the response options were adequate, compared to 100% of participants from site B where the response options were amended (see section 6.4.9) before pilot testing. All results and comments are shown in Appendix 8.

6.4.4 Usability of PANA_Attitudes Questionnaire

In the PANA_Attitudes Questionnaire, 100% of participants from both sites A and B indicated that the questionnaire was easy to complete, and 100% of participants at both sites also indicated that the questions were clear and easy to understand, and had a logical flow. The majority of participants from site A (n=24) and site B (n=22) indicated that the questionnaire took between five and ten minutes to complete. Ninety-seven percent (n=27) from site A and 97% (n=29) from site B indicated that the response options were adequate. All results and comments are presented in Appendix 8.

6.4.5 Mean scores

Responses for the PANA_Knowledge Questionnaire were 'True', 'False', 'Don't Know'. There were twenty-eight knowledge items. Correct responses to the knowledge items were scored one point and incorrect or 'don't know' responses scored zero. A total score was obtained by summing all correct responses.

Skills responses were converted to the numerical values of one (= I do this every time I provide care, as necessary/I know how to do this) and zero (= I do

not know how to do this/I am unsure how to do this) to calculate the mean number of positive responses, standard deviations, and confidence intervals (lower and upper) for skill items.

The response options for the PANA_Attitudes Questionnaire were converted to points: one point for strongly agree (5) or agree (4), as they reflect a more positive attitude, and zero for unsure (3), disagree (2), and strongly disagree (1). Three items were reverse-scored (items 2, 3 and 9) as they were negatively worded. All scores of one were added to obtain the mean.

Mean correct scores for all knowledge, skill and attitudinal items across the three groups of participants are presented in Table 23. The results from all three instruments show a range of scores denoting either correct or positive responses. Correct scores on the PANA_Knowledge Questionnaire ranged from 57% (participant in group 2) to 92% (participants from groups 1 and 3), indicating varying levels of knowledge. The skill responses show a mean of 36.1, indicating that participates assessed themselves as knowing how to do the named skill in the majority of items. The PANA_Attitude Questionnaire demonstrated a range of positive attitudes for the 19 attitude items from 100% to 37.8%.

There was little variation between responses between the three groups of nursing assistant participants overall. The mean score of Group 1 was 23.6 correct responses out of a possible 28 (range 19–25). Group 2 had a mean score of 23.7 (range 20–25) and Group 3 a mean score of 23.3 (range 21–25). At site B, the mean score for Group 1 was 24.5 (range 23–26), Group 2, 21.5 (range 16–

25) and Group 3, 22.8 (range 18–26). There was little difference in knowledge scores between the groups at both sites (see Appendix 8). Interestingly, Group 1 had more correct responses than Group 3.

6.4.6 Item discrimination

Participant feedback indicated that the knowledge items were deemed to be within the range of easy to moderately difficult. This is supported by the mean percentage of combined correct scores (82.2%), as shown in Table 23. The mean number of correct responses out of a possible 28 for Group 1 was 23.6 (range 19–25), with Groups 2 and 3 having a mean of 22.8 correct responses (range 20–25 and 21–25 respectively). While there was little difference in knowledge scores between the groups, those with the least experience in Group 1 had a higher mean correct response than the more experienced participants in Groups 2 and 3, with the lowest score being recorded for Group 2, the second most experienced set of nursing assistants.

The mean number of positive responses for the PANA_Skills Questionnaire on practice, i.e. 'I do this every time I provide care, as necessary' (Site A), 'I know how to do this' (Site B) was 35.8 out of a possible 38 for Group 1, 36.3 for Group 2, and 36 for Group 3. The mean number of positive responses for the PANA_Attitudes Questionnaire indicated Group 1 was the most positive (M = 15.9) followed by Group 3 (M = 15.3), with Group 2 having the least positive attitudes (M =14.6). For differences in attitudes between sites, see Appendix 8. The most positive attitudes shown by the results in this pilot sample are those in Group 3 at site A and Group 1 at site B. Group 1 at site A and group 2 at site B

were the least positive. The PANA_Attitudes Questionnaire indicated good variability across all items with the exception of Item five, 'Explaining the purpose of my care demonstrates respect even when a person is unable to respond', a statement derived almost verbatim from the qualitative work of item generation in Phase 1. This item showed very strong agreement within the sample in the pilot study, and as such may be of little use in differentiating between positive and negative opinions.

Table 23

Phase 3 descriptive statistics by group

Group	PANA	N	Range	Total mean number correct/positive responses (SD), [95% CI, lower–upper]	% correct or positive
Group 1 (<2 years experience)	Knowledge	12	19–26	23.6 (1.92) [1.08, 22.5–24.7]	84.5
	Skills	11	32–38	35.8 (1.94) [1.14, 34.6–36.9]	94.2
	Attitudes	11	14–19	15.9 (1.30) [0.76, 15.1–16.6]	83.7
Group 2 (2–5 years experience)	Knowledge	17	16–25	22.8 (2.61) [1.24, 21.6–24.1]	81.7
	Skills	17	25–38	36.3 (3.29) [1.56, 34.7–34.9]	95.6
	Attitudes	16	7–18	14.6 (2.55) [1.25, 13.3–15.8]	76.6
Group 3 (5+ years experience)	Knowledge	32	18–26	22.8 (1.94) [11.0, 11.7–33.9]	81.6
	Skills	32	22–38	36 (3.21) [1.11, 34.9–37.2]	94.9
	Attitudes	30	8–18	15.3 (2.15) [0.77, 14.5–16.0]	78.7

6.4.7 Combined results from Site A and Site B

Results from both sites were finally combined to give a total mean number of correct responses, standard deviations, percentage of correct responses and

confidence intervals for the three new instruments: PANA_Knowledge Questionnaire, PANA_Skills Questionnaire and PANA_Attitudes Questionnaire as shown in Table 24.

The results from all three instruments show a range of scores denoting either correct or positive responses. Correct scores on the PANA_Knowledge Questionnaire ranged from 57% (participants in Group 2) to 92% (participants from Groups 1 and 3), indicating varying levels of knowledge. The skill responses show a mean of 36.1, indicating that participants assessed themselves as knowing how to do the given skill for the majority of skill items. The PANA_Attitude Questionnaire demonstrated a range of positive attitudes for the 19 attitude items from 100% to 37.8%.

The groups from the two pilot sites were not equal; site-specific data is shown in Appendix 8 and shows slight differences between the two. Group 1 at site A indicated that they did not know or were unsure how to do a given skill in more responses than group 2 and 3. At site B, Group 1 indicated that they knew how to do the skill in all except two of the 76 responses for the 38 skills in the PANA_Skills Questionnaire, and Group 2 indicated that they did not know or were unsure how to perform a skill in more responses than the other groups. The least experienced staff at site A responded less positively to more skill items than the other two groups. At site B, staff with between two and five years' experience responded negatively to more items. No conclusions can be drawn from this data due to the unequal groups and small sample.

Table 24

Phase 3 descriptive statistics combined results

Instrument	**n**	**Range**	**Mean number of correct/positive responses (SD) [95% CI]**	**% Correct/positive**
PANA_Knowledge Questionnaire	61	16–26	23 (2.13) [0.53, 22.4–23.5]	82.2
PANA_Skills Questionnaire	60	22–38	36.1 (3.00) [0.76, 35.3–36.8]	95
PANA_Attitudes Questionnaire	57	7–19	15.1 (2.19) [0.57, 14.5–15.7]	89.6

*Note: 10% missing data for skill items

6.4.8 Online surveys

Results of the online and paper responses are shown in Appendix 8. All participants who completed the online questionnaire at site A were from Group 2 (n=10). A comparison of the online and paper-based surveys showed a variation in responses for ten of the 28 knowledge items (36%) in that they trended towards incorrect responses when answered online. These were:

1. A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.

2. A palliative approach supports comfort but does not provide a cure.

5. A palliative approach is offered when treatment will not help the person to live longer.

11. It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.

12. The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.

14. Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.

15. When a person is receiving pain relief, they no longer feel pain.

18. Families or carers who know the person best are usually the first to detect changes in a person's condition.

22. Spiritual care identifies what is important to a person.

27. When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.

There was no evidence that the knowledge items discriminated between groups of participants across the two sites, either online or in paper format, based on this small sample. The small variation in results from the online and paper-based instrument at sites A and B can be attributed to natural variability.

6.4.9 Amendments to questionnaires

The following items for knowledge were amended based on feedback from participants:

8: Providing a palliative approach is based on the individual's needs and wishes: amended to 'A palliative approach is based on individual needs'.

10: Families can often experience grief before the death of their family member: amended to 'Families often experience grief before the death of their family member'.

Based on feedback for the PANA_Skills Questionnaire (see Appendix 9), the response options for this questionnaire were amended as follows:

From	To
• I do this every time I provide care, as necessary. • I do not know how to do this. • I am unsure how to do this	• I know how to do this. • I am unsure how to do this. • I do not know how to do this.

In addition, 'I' was removed from the beginning of each skill item and placed in the stem; e.g., Item 6, 'I listen attentively to the people I care for' was changed to to 'listen attentively to the people I care for'.

6.4.10 Open-ended responses

A total of 28 comments and suggestions were made by participants. General responses that did not address a specific usability aspect of the instrument were reviewed. The mostly frequently mentioned issues across participants' responses were identified. The following quote provides an example of a response about English-language ability:

> Many women entering aged care as AINs are of many diverse cultures. Their English is not good. Many speak their own language at home. This can, and does, cause a lack of understanding on their part. They are able to provide the personal care but lack the discernment and ability to communicate changes in residents' conditions. As this trend continues, in my opinion, the quality of care deteriorates. (Participant site B, Group 3)

English-language proficiency is identified not only as a barrier to answering the

skill items but, more broadly, to the delivery of quality care, as evident in the above comment. Yet one in ten permanent residents in aged care facilities in Australia were identified as speaking a language other than English at home (Australian Institute of Health and Welfare, 2016), so the increase in foreign-born workers can be seen to reflect cultural diversity and confer benefits in care provision (Negin et al., 2013). It is worth noting that while 53% of Group 3 were born outside Australia, the Australian-born number of participants across all groups (34/61) was greater than 50% ,which may not represent the cultural and linguistic diversity of the workforce in metropolitan Sydney (Ronaldson et al., 2008) or within the Australian aged care workforce at large (Negin et al., 2013).

Another frequent response by participants was gratitude 'for the opportunity' to participate in this study. This reflects other findings on the importance of nursing assistants having a voice, especially in the context of their involvement in providing a palliative approach and end-of-life care (Fryer et al., 2016).

Direct responses to the question on the difficulty of items showed that most participants found the items easy to moderately difficult to answer. Some struggled however, as indicated by the following statement from one participant at site A in Group 3: 'To answer these questions, you should be a nurse [sic] for more than three years and above'. This participant who had more than five years' experience in the role indicated that items were sufficiently challenging for those with less than three years' experience.

The responses to the attitude items identified one participant's concern with

confidentiality, professionalism and training influencing nursing assistants' quality of care:

> Sharing experiences with other staff always needs to be done in a professional way i.e. confidential [information] that benefits the resident or the quality of care that is given to a resident, these discussions should be done privately. (Participant site B, Group 1)

Importantly, the following comment, framed within the recent decision of the New South Wales Parliamentary Enquiry (2016) not to support the existing legal requirement for RNs to be present around the clock in RACFs (and in effect removing this requirement) makes a strong case for the ongoing training and development of nursing assistants:

> [The] majority of AINs have no idea how to provide palliative care. Additional training to understand palliative care needs to be included in Cert 3 and 4. When I did Certs [sic] approximately 15 years ago very little was mentioned. I have learned a lot from my RN I have worked under last ten years. (Participant at site B, Group 3)

6.5 **Chapter summary**

This chapter has presented the aim, data collection method, sample, data analysis procedures and results of the pilot test. Results show that all three questionnaires within the instrument appeared to perform well on usability, clarity and flow of questions, and were time-efficient. Results from this pilot test enabled refinement of the data collection method and analysis plan, plus minor modifications to the instrument, and gave the researcher experience in collecting data within this study's chosen methodology. The next chapter

presents the results of the field study conducted in Phase 4, the final phase of the study, to validate the instrument for use with nursing assistants in RACFs.

Chapter 7 Phase 4: Instrument Testing

7.1 Overview

This last phase of the study is to establish a final set of items that meet established criteria for validity and reliability. In the first analysis, individual item properties are evaluated for item discrimination and difficulty, item-total correlation, and internal reliability. The processes used to eliminate least discriminating items are described. In the second analysis, the procedures to further test the instrument's psychometric properties, including testing the study's specific hypotheses, are detailed, along with the results. The chapter concludes by summarising the combined analyses that resulted in an instrument comprising three separate questionnaires: PANA-Knowledge Questionnaire (17 items), the PANA_Skills Questionnaire (13 items) and the PANA_Attitude Questionnaire (10 items).

7.2 Aim

The aim of this fourth and final phase of this study was to test the psychometric properties of the new instrument in its final form for use both as one single instrument and as three separate instruments for evaluating nursing assistants' knowledge, skills and attitudes within a palliative approach in RACFs.

7.3 Method

A random sample of RACFs (n=17) was used to recruit participants. The survey method was adopted for data collection using the paper-based and online surveys which had been trialled in the Phase 3 pilot test. Both modes of

administration have shown advantages and disadvantages in nurse workforces, yet in combination can reach a large number of participants (Reitz & Anderson, 2013; Wu et al., 2012). It is anticipated that both modes will be used to administer the finalised instrument in the future.

7.3.1 Sample and setting

Random sampling was chosen for this final phase to minimise bias in the selection process of sites and to ensure the inclusion of a range of different sized facilities from both the profit and not-for-profit sectors. The Aged Care Service List (Australian Government Department of Social Services, 2014) was used to select RACFs, both residential low care and high care, in the Greater Sydney area (n=721). Twenty of such 721 sites with more than 50 places were randomly selected for recruitment, on the basis that facilities with operational places greater than 50 would have a mean ratio (worker: resident) of 0.7 direct care workers and that these would be predominantly nursing assistants (Mavromaras et al., 2017): even if all the selected twenty sites had only the minimum 50 places, this would yield 700 direct care workers. A minimum sample of 300 participants was needed, based on statistical advice and 'rules of thumb' for sample sizes (Clark & Watson, 1995; Field, 2009; Rouquette, 2011). This number represents a sufficiently large sample for evaluating inter-item correlations (Polit & Beck, 2017).

7.3.2 Recruitment

The directors of nursing (DONs) or care managers at these RACFs were contacted by phone and asked if they would like to participate in this phase of

the study. Facility managers who expressed interest were sent the participant information sheet and flyer for Phase 4 by email (see Appendix 2 and 3). Following agreement to participate from the DONs and care managers, multi-coloured flyers advertising the study were distributed to the RACFs, informing nursing assistants that the survey instrument could be completed either on line or in paper format. A date was set for delivery of the instrument booklets and a collection box, according to the location of the RACFs.

Six sites initially declined to participate:

- One was a psychogeriatric facility that did not provide ageing in place, and therefore did not cater for residents with high care needs.
- The care manager of another site was taking extended sick leave.
- A third site expressed concern about staff not being sufficiently proficient in English to complete the survey, and about the time survey coordination would take.
- Three sites belonged to national organisations and required permission from the organisation prior to agreeing to participate. Permission was later granted for two of these sites.

After two months of data collection proceeding slowly in the remaining 14 of the initial 20 sites, a randomly selected back-up site agreed to participate. Altogether, 17 sites were included, with 1888 operational places yielding a potential sample of 1321 nursing assistants.

7.3.2.1 Inclusion criteria for participants

All nursing assistants providing direct care to residents from the participating RACFs were eligible to join the study. The number (or approximate number) of nursing assistants working in each facility was provided by the DON or care manager.

7.3.2.2 Test-retest subsample

A subsample of thirty nursing assistants was sought to complete the survey a second time for the purpose of test-retest reliability and responsiveness. The sites were selected based on the four DONs or care managers who had responded enthusiastically to the initial invitation. The decision to split the re-test among participating sites was to avoid burdening any one site, as well as to gain a range of participants from different organisations.

7.4 Data collection

One thousand printed instrument booklets were distributed over an initial 3-day period in mid-2015, and provided an opportunity for the researcher to meet the DONs or care managers face to face, discuss the study in more detail, and clarify the data collection processes. An instrument booklet was provided for each eligible participant employed in the facility unless a specific number of participants was nominated by the care manager. The instrument booklets were designed to reflect the online survey accessed through the web link to SurveyMonkey, and the link to the online version in SurveyMonkey was provided on flyers and on the paper copies.

7.4.1 Instrument booklet

The instrument booklet was compiled as a 16-page A4 booklet containing the three questionnaires developed and refined in Phases 1, 2 and 3, and the Palliative Care Quiz for Nurses (PCQN) (Ross et al., 1996). Participant information, agreement to participate and demographic items were presented at the beginning of the booklet. For each instrument, instructions and generic information preceded its set of items. The order of the questionnaires remained the same as in the pilot study, with the PCQN presented as the final questionnaire.

7.4.1.1 PANA_Knowledge Questionnaire

This questionnaire consisted of 28 items testing nursing assistants' knowledge of a palliative approach. Response options to each knowledge item were True/False/Don't Know, based on the format of the PCQN.

7.4.1.2 PANA_Skills Questionnaire

The second questionnaire comprised 38 skill items, the purpose of which was to identify nursing assistants' skills when providing care with a palliative approach. The response options were: I know how to do this; I am unsure how to do this; I do not know how to do this.

7.4.1.3 PANA_Attitudes Questionnaire

The third questionnaire comprised 19 attitudinal statements, the purpose of which was to understand how nursing assistants feel about providing care with a palliative approach. A five-point Likert scale was used to collect responses, a

number shown to be both reliable and low enough for participants to answer quickly (Wakita, Ueshima, & Noguchi, 2012). Responses options were: Strongly Agree (SA); Agree (A); Unsure (U); Disagree (D); Strongly Disagree (SD).

7.4.1.4 Palliative Care Quiz for Nurses (PCQN)

The fourth and last instrument was the PCQN which is a 20-item quiz designed to test nurses' knowledge of palliative care. The 20 items of the quiz are presented in Appendix 9. Response options in the quiz were True/False/Don't Know.

This instrument was validated for paper-based administration in the original study by Ross et al. (1996). It was administered in this study in web-based format in addition to paper copy, although this is unlikely to have influenced overall results. Permission to use the PCQN was sought by email (20/10/2014) from the person responsible for overseeing the PCQN on behalf of the authors. The inclusion of this instrument was to test hypothesis I of this study (sections 3.2.2 and 7.5.4.1) that an instrument designed specifically for nursing assistants' level of education and scope of practice will perform better than the PCQN in discriminating knowledge between groups of nursing assistants based on years of experience.

7.5 **Analysis**

This section outlines all the analysis procedures used in this phase to establish the individual item properties, validity and reliability of the instrument.

All analyses were conducted in Excel and the Statistical Package for the Social

Sciences (SPSS) version 22 (IBM, 2013).

7.5.1 Data entry check

Before formal analysis of the data commenced, a check was conducted on a sample of surveys to confirm the accuracy of data entry. A check of total data entry points across 36 surveys was completed (105 items x 36 = 3780). This accounted for approximately ten per cent of all data entries excluding re-test data. The acceptability for error was set at 1%, which corresponds to a standard class of error and allows for 37.8 errors across the 3780 responses (Thimbleby & Cairns, 2010). The data entry check found 11 errors, amounting to 0.29%. These were corrected in the sample and the data set was confirmed as of acceptable quality for analysis.

7.5.2 Analysis procedures

Prior to analysis, correct responses to all knowledge items were scored one point, and incorrect or 'don't know' responses scored zero. A total scale was obtained by summing all correct responses. For the skills items, one point was scored for 'I know how to do this' and zero for 'I am unsure how to do this' or 'I don't know how to do this'. To determine a discrimination index for the attitudinal items, initial responses were scored as follows: Strongly Agree (SA) was scored 5, Agree (A) =4, Unsure (U) =3, Disagree (D) =2, Strongly Disagree (D) =1. The total positive score for attitudinal items was 95. For the individual item analysis, these scores were recoded: 5 and 4 recoded as 1; and 3, 2 and 1 recoded as 0. Three items (number 2, 3, and 9) were reverse-scored. The total maximum score for the attitudinal items was 19. The scaled responses of 5 (SA)

to 1 (SD) were retained to optimise correlations for the factor analysis, as five or more categories are necessary to test linear data (Streiner & Norman, 2008).

7.5.3 Individual item analysis

Item difficulty and item discrimination provide important information about the performance capabilities of items to differentiate levels of the attributes being tested across the target population (DeMars, 2010; DeVellis, 2012). Item discrimination and item difficulty indices are used to measure the reliability of scores and are independent of one another: an item can be easy or difficult whether it is discriminating or non-discriminating (DeMars, 2010). Difficulty and discrimination indices provide the criteria for item inclusion in the definitive version of the new knowledge instrument. Item difficulty analysis was not applied to the attitudinal items on the basis that attitudes are neither correct nor incorrect; nor was it applied to the self-reported skills items.

7.5.3.1 Item-score correlations

The two types of item-score correlations are the correlation between an item and a total score including the item, and the correlation between an item and a total score omitting the item (Polit & Yang, 2016). The second approach is also called the 'corrected approach'. In test scores, the item-total correlation indicates how well each item differentiates between participants who know the content and those who do not (Pope, 2009). As such, the performance on an individual item is predictive of the overall test, with participants who know the content gaining a higher positive coefficient score on each item and high overall assessment scores (Nunnally & Bernstein, 1994).

The corrected item-total correlation indicates the correlation of each individual item with the total instrument omitting that item. Using SPSS, the corrected item-total correlation was calculated in the reliability procedure.

7.5.4 Validity analysis

Three types of measurement-related validity were examined to confirm the PANA instrument's construct validity. These measures of construct validity were:

- Known groups (discriminative validity)
- Convergent validity
- Divergent validity

In the absence of a gold standard, the construct validity of a new instrument can be tested by the extent to which it can discriminate between groups known or expected to differ with regard to the construct of interest (Polit & Yang, 2016). This is a widely used method to test construct validity, and was adopted in this study because many nursing assistants in RACFs are likely to have been recruited from the broad labour market representing retail, hospitality, clerical and cleaning work (Mavromaras et al., 2017).

As well, the extent to which the new, focal measure converges or diverges with different measures of the same or theoretically similar constructs provides support for construct validity. Convergent validity indicates a correlation between the new, focal measure and a measure which is conceptually similar (Polit & Yang, 2016). Divergent validity tests the extent to which measures of

different constructs correlate with one another (DeVon et al., 2007; Polit & Beck, 2017). In this study, the PCQN, a theoretically relevant instrument, was used to measure convergence and divergence (DeVellis, 2012; Polit & Yang, 2016). The new instrument needs to be sufficiently different from the existing instrument to justify its development, although comparison does allow a degree of convergence.

7.5.4.1 Construct validity: structural validity

The primary goal of instrument validation is to confirm the new instrument measures what it is supposed to be measuring, namely the construct of interest (Frytak, 2004; Nunnally, 1994; Polit & Yang, 2016). The theoretical construct of a palliative approach is not guaranteed by the items themselves and needs to be empirically tested. Construct validity includes structural validity, which is concerned with establishing whether an instrument captures the hypothesised dimensionality of a construct (Polit & Beck, 2017). The validation process examines the interrelationships among variables such that all variables represented by the correlations relate to the same construct. This process provides the evidence that the construct is well defined (Nunnally & Bernstein, 1994).

Exploratory factor analysis is the most commonly used procedure in the instrument development process to identify interrelationships between items and examine the underlying or latent construct. In an exploratory factor analysis, there are no a priori assumptions about underlying dimensions (Frytak, 2004).

7.5.5 Reliability analysis

Reliability is a measure of consistency and reproducibility (Frytak, 2004). It is not fixed, and depends upon the instrument or test, the group to whom it is administered, and the circumstances of its administration (Streiner, 2013). There are a few indices of reliability that each provide a different reliability estimate. The types of reliability used in this validation phase were internal consistency and test-retest reliability.

7.5.5.1 Internal consistency

Cronbach's alpha coefficient (α) is a common measure of internal consistency used to measure reliability and inter-relatedness of items. An acceptable level of alpha cited for research instruments is 0.70–0.80 (Meyer, 2010; Nunnally, 1994; Streiner, 2013).

7.5.5.2 Test-retest reliability coefficient

Another form of reliability is test-retest reliability, used to determine if the instrument is stable over time (Meyer, 2010). An assessment of consistency is made by comparing participants' mean scores on the first administration of the instrument with those attained on a second administration. The usual method, and that used by Ross and colleagues in the PCQN (1996) to calculate test-retest reliability is to calculate a Pearson's correlation coefficient between the two scores. A coefficient +1 indicates that the two variable are perfectly positively correlated. Values of +.1 represent a small effect, +.3 is a medium effect and +.5 is a large effect (Field, 2009).

7.6 Results

7.6.1 Recruitment and participants

Recruitment was conducted over an eight-month period and included the re-test. A total of 17 sites participated in phase four of the study, with a total workforce of approximately 1233 nursing assistants. Of these eligible participants, 28 per cent (n=343) completed the whole survey instrument, either in paper format or online.

Twenty participants from one site only participated in the test-retest. Of these, four did not complete the instrument a second time and another did not complete the PANA_Attitudes Questionnaire a second time. Sixteen participants were therefore eligible for inclusion in the retest; of these, one participant was not eligible to complete the PANA_Attitudes Questionnaire.

7.6.2 Demographic characteristics

Nursing assistants (n=353) across the 17 sites completed the demographic questions. Of this sample 86% (n=304) were female and 14% male (48). Of these, 82% (n=291) indicated that they were not born in Australia. Fifty-two countries were identified as the country of birth for those not born in Australia. The majority at 36% (n=126) were between 25 and 34 years of age and Certificate III in Aged Care was the highest level of education held by 39% (n=138). Forty-one per cent (n=145) had been employed in their role for more than five years and 25.2% (n=89) for less than two. Five participants did not proceed to the first questionnaire.

Role descriptions included Assistant in Nursing (AIN), care companion, care staff, aged care worker, care services employee, personal carer/care assistant. An RN and EN identified in the demographic data were excluded.

Table 25

Demographic characteristics of sample Phase 4

Variable		**Descriptive statistics**
Group 1 (n=89)		**25.2%**
Gender		(%)
	female (n=75)	84.3
	male (n=14)	15.7
Age mean (years) [SD] (missing data =5)		30 [8.36]
Years range		21-59
Australian-born		11.3 %
Highest education		%
	Year 10 or equivalent (n=4)	4.5
	Year 12 or equivalent (n=9)	10.1
	Cert. 3 Aged Care (n=48)	53.9
	Cert. 4 Aged Care (n=11)	12.4
	Diploma or Certificate TAFE (n=11)	9.0
	Undergraduate (n=9)	10.1
Group 2 (n=119)		**33.7%**
Gender		(%)
	female (n=101)	84.9
	male (n=18)	15.1
Age mean (years) [SD] (missing data =6)		38 [10.87]
Years range		23-64
Australian-born		35.5 %
Highest education		%
	Year 10 or equivalent (n=2)	1.7
	Year 12 or equivalent (n=8)	6.7
	Cert. 3 Aged Care (n=47)	34.1
	Cert. 4 Aged Care (n=26)	21.8
	Diploma or Certificate TAFE (n=15)	12.6
	Undergraduate nursing (n=21)	17.6
Group 3 (n=145)		**41.1%**
Gender		%
	female (n=128)	88.3
	male (n=17)	11.7

Variable		Descriptive statistics
Age mean (years) [SD] (missing data =5)		49 [11.18]
Years range		24-70
Australian-born		53.2 %
Highest education		%
	Year 10 or equivalent (n=9)	6.2
	Year 12 or equivalent (n=6)	4.1
	Cert. 3 Aged Care (n=43)	29.7
	Cert. 4 Aged Care (n=57)	39.3
	Diploma or Certificate TAFE (n=20)	13.8
	Undergraduate (n=10)	6.9

Note: * missing cases 1.7% sample

7.6.3 PANA_Knowledge Questionnaire

7.6.3.1 Mean scores

Individual item analysis on the PANA_Knowledge Questionnaire and the total correct responses for each item across the three groups are shown in Appendix 10. The maximum, minimum and mean score, and standard deviation and standard error for each group for both the PANA_Knowledge Questionnaire and the PCQN, are shown in Table 26. Correct responses on the PANA_Knowledge Questionnaire ranged from 7 to the maximum score of 28 corresponding to level of experience in role.

By comparison, scores on the PCQN ranged from 0 to a maximum score of 20. This score was recorded from within group 1, the least experienced group.

Table 26

PANA_Knowledge Questionnaire, PCQN descriptive statistics

	N	Mean	Std. Dev.	Std. Error	95% Confidence Interval	Min	Max
Score PANA_Knowledge Questionnaire					Lower/Upper Bound		
Group 1	88	22.07	3.297	.351	21.37/22.77	7	26
Group 2	116	22.15	2.893	.269	21.61/22.68	8	27
Group 3	144	22.84	2.265	.189	22.47/23.21	16	28
Total	348	22.41	2.782	.149	22.12/22.71	7	28
Score PCQN							
Group 1	80	6.63	3.180	.356	5.55/7.00	0	20
Group 2	112	6.21	3.418	.323	5.53/6.79	0	14
Group 3	134	6.92	3.179	.275	6.28/7.36	0	14
Total	326	6.60	3.268	.181	6.11/6.82	0	20

Figure 2 shows the mean knowledge scores between groups based on experience for both the PANA_Knowledge Questionnaire and the PCQN. The means scores reflected in the graph show little difference in distribution of scores between groups for both instruments. However, comparing the range of scores across the PANA_Knowledge and the PCQN, floor effects in knowledge scores can be seen for the PCQN, greatly limiting its sensitivity in this population.

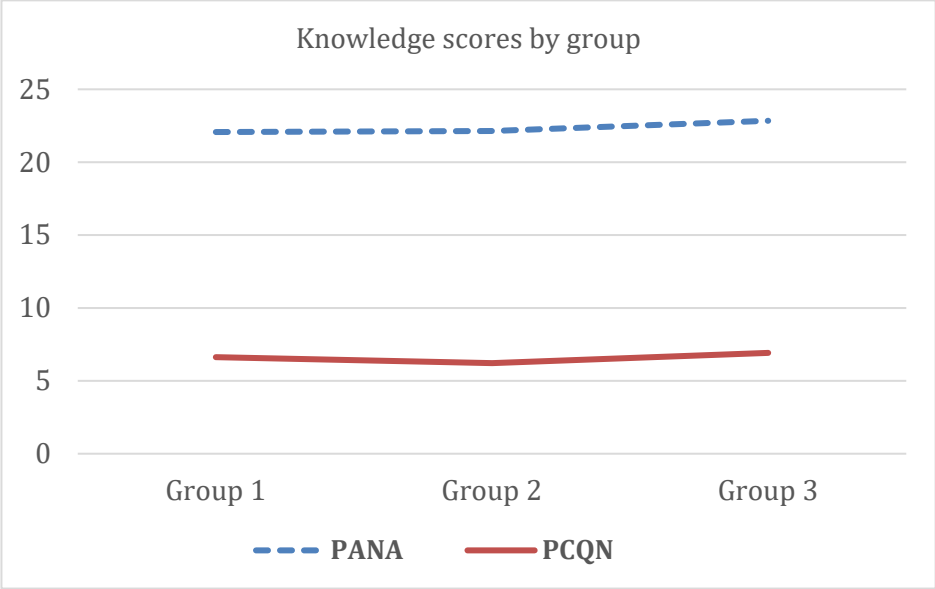

Figure 2 Mean knowledge scores PANA vs PCQN for experience in role

7.6.3.2 Individual item properties

The results of the Item Discrimination Index and the Item Difficulty Index are presented in Table 27. These analyses identify the items that are least effective in discriminating between high and low scorers on the new instrument and provide the percentage of participants who scored each item correctly. A random half of the sample (n=174) was used for both analyses, using the top 25% of scorers (n= 43) and the bottom 25% of scorers (n=43). The number of correct items for each set was calculated, and for each item, the percentage of participants in each group who answered correctly was obtained. The two percentages (high scorers minus low scorers) were then subtracted from each other to arrive at the item's discrimination index. The decision to retain an item was based on a positive discrimination index above .20 (D'Sa & Visbal-Dionaldo, 2017; Ross et al., 1996; Rush, Rankin, & White, 2016).

The item difficulty index provided the percentage of participants in the half-sample who scored each item correctly. Items that are answered either correctly or incorrectly by a high percentage of participants (e.g. 95% or more) do not allow any discrimination among the users of the instrument and are candidates for deletion (Clark & Watson, 1995). These items cause ceiling and floor effects within the questionnaire data and detract from the instrument's psychometric validity (Streiner & Norman, 2008; Wang, Zhang, McArdle, & Salthouse, 2008). The item difficulty index values used in this study were 0.10 and 0.90. Values below 0.10 and above 0.90 indicate that that most participants were not able to answer the item (0.10) or that most answered correctly (0.90). The difficulty index appears in Table 27. Items that achieved a difficulty index of less than 0.10 or greater than 0.90 in conjunction with the item discrimination index were considered for deletion.

For the PANA_Knowledge Questionnaire, high scorers answered between 24 and 27 items correctly (M = 25, SD = 0.67); low scorers answered between 8 and 20 items correctly (M = 18.2, SD = 2.77). Twelve items were candidates for deletion, based on values below 0.10 and above 0.90 for difficulty and a negative discrimination index below 0.20. These items can be seen in Appendix 10. Although item 3 scored 0.92 in the difficulty index, it was retained because those with less than 2 years' experience and those with 2–5 years' experience

scored 0.87 and 0.88 respectively,[5] indicating that for the majority of participants this item was within the defined limits of difficulty.

The item-total correlations are presented in Table 27. Recommendations for item-total correlations vary, with Streiner and Norman (2008) suggesting that items lower than 0.20 are candidates for deletion while Pope (2009) states that a positive coefficient between 0.20 and 0.39 indicates good discrimination and values above 0.40 indicate very good discrimination. In this study, an item-total correlation of 0.20 or greater, along with the item discrimination and item difficulty indices, was used to determine if an item should be considered for deletion. Among the items, the item-total correlations ranged from 0.14 to 0.37 (M = 0.25, SD = 11.09). The guideline of 0.15–0.50 was used as the range in which inter-item correlations ideally should fall, based on the premise that a palliative approach is a broad concept (Clark & Watson, 1995). Four items had item-total correlations less than 0.20[6] and were removed, as they did not achieve scores above 0.10 or less than 0.90 in difficulty or above 0.20 in discrimination. While item 22 scored above 0.10 and less than 0.90 for difficulty, the low item-total correlation made it too a candidate for deletion.

For 16 knowledge items retained following the individual item analyses, Cronbach's alpha equalled 0.69 (reduced from 0.79 on the original 28 items). To ensure alpha did not drop below the acceptable lower limit of $\alpha = 0.70$ (DeVellis, 2012; Nunnally, 1994), items 10 and 18 were also retained as these

[5] Refer to Appendix 10.
[6] items 21, 22, 23, and 26 – see Appendix 10.

items both had scores below 0.90 for difficulty among the three groups of nursing assistants. Retaining these items increased alpha to 0.72 and enhanced content coverage. The removal of item 22 further improved Cronbach's alpha from $\alpha = 0.72$ to $\alpha = 0.74$. A total of 17 items were retained as the final set for the PANA_Knowledge Questionnaire.

Table 27

Item characteristics PANA_Knowledge Questionnaire

no.	Item	Discrimination Index	Difficulty Index	Item-total correlation	Alpha if item removed	Final alpha
1.	A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.	23	.87	.40	0.79	0.72
2.	A palliative approach supports comfort but does not provide a cure.	33	.87	.41	0.79	0.73
3.	A palliative approach may be required for some people for months or years while for others it may be required for hours or days.	21	.92*	.39	0.79	0.72
4.	The needs of people requiring a palliative approach are the same.	39	.67	.37	0.79	0.73
5.	A palliative approach is offered when treatment will not help the person to live longer.	41	.79	.40	0.78	0.72
6.	People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative approach.	44	.74	.39	0.78	0.72
10.	Families can often experience grief before the death of their family member.	16	.90*	.37	0.79	0.73
11.	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.	27	.29	.27	0.79	0.74
12.	The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.	25	.89	.40	0.79	0.72

13.	Identifying symptoms (physical signs) is the first step in being able to manage symptoms.	20	.85	.39	0.79	0.72
14.	Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.	30	.87	.39	0.78	0.72
15.	When a person is receiving pain relief, they no longer feel pain.	39	.75	.31	0.79	0.73
18.	Families or carers who know the person best are usually the first to detect changes in a person's condition.	19	.91*	.38	0.78	0.73
19.	A person expressing a wish to die means that the person will die soon.	27	.83	.21	0.79	0.74
24.	Bladder and bowel problems can cause discomfort when a person approaches the end of life.	25	.88	.29	0.79	0.71
27.	When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.	37	.65	.19	0.80	0.75
28.	Signs that death is near can be present hours to days before death occurs.	33	.71	.24	0.79	0.74

Note: Items removed from the scale are shown in Appendix 10.

7.6.4 PANA_Skills Questionnaire

7.6.4.1 Mean scores

The maximum, minimum and mean scores, and standard deviation and standard error by group for the PANA_Skills Questionnaire, are shown in Table 28 below. The direction of scores for the PANA_Skills Questionnaire reflects positive responses to skill items based on experience. All groups recorded the maximum number of positive responses (38).

Table 28

PANA_Skills Questionnaire descriptive statistics

	N	Mean	Std. Deviation	Std. Error	Min	Max
PANA_Skills Q						
Group 1	87	34.72	4.048	.434	19	38
Group 2	115	35.24	3.565	.334	19	38
Group 3	141	35.63	3.585	.294	18	38
Total	343	35.27	3.708	.199	18	38

7.6.4.2 Individual item properties

The results of the item discrimination, item-total correlation and alpha values for skills items are presented in Table 29. High scorers (n=43) responded positively ('I know how to do this') to all items. Low scorers responded positively to between 18 and 34 items (M = 30.3, SD = 3.015). Twenty-five items were candidates for deletion based on a discrimination index below .20. The thirteen retained items correlated above 0.30. Two items correlated above 0.50 (33, 35) and were retained as they had values above 0.20 for discrimination.

Cronbach's alpha for individual items if the item was removed from the scale was between 0.79 and 0.81, with the final alpha on the remaining 13 items equal to 0.81. A total of 13 items were retained as the final item set for the PANA_Skills Questionnaire.

Table 29

Item characteristics PANA_Skills Questionnaire

Item no.	Item	Discrimination Index %	Item-total correlation	Alpha if item removed	Final Alpha
1	Observe what a person can do without assistance	21	.44	.93	.80
3	Assist in updating care plans	47	.34	.93	.81
9	Direct families to other members of the care team when they need further advice	42	.47	.93	.80
13	Care for a person with challenging behaviours	26	.52	.93	.80
14	Raise the concerns of (advocate for) the individuals in my care	30	.44	.93	.80
16	Observe for pain using a valid and reliable pain assessment tool	63	.41	.93	.79
18	Provide non-medication strategies, such as gentle massage, in order to manage pain	49	.48	.93	.79
19	Evaluate the effectiveness of pain management strategies using a validated pain assessment tool	77	.41	.93	.79
27	Contribute to problem solving to seek solutions	28	.43	.93	.80
29	Recognise the signs when an individual is in the last days or hours of life.	42	.45	.93	.80
31	Attend to a dying individual's care	23	.50	.93	.80
33	Find ways to cope with my own emotional responses when a person I have been caring for has died	21	.51	.93	.80
35	Reflect on what I say and do when providing a palliative approach.	23	.57	.93	.80

Note: Items removed from the instrument are shown in Appendix 10.

7.6.5 PANA_Attitudes Questionnaire

7.6.5.1 Mean scores

For the attitudinal items, mean scores on individual items were calculated for each of the three groups based on the total number of positive responses: Strongly Agree/Agree or Strongly Disagree/Disagree. Results by group are shown in Appendix 10. The maximum, minimum and mean scores, and standard deviation and standard error by group on the PANA_Attitudes Questionnaire, are shown in Table 30. Group 1 returned the fewest positive responses (M=14.8, SD=2.581) (78%) and recorded the lowest minimum score of 0 out of the possible 19 positive responses.

Table 30

PANA_Attitudes Questionnaire descriptive statistics

	N	Mean	Std. Deviation	Std. Error	Min	Max
Score PANA_Attitudes Q						
Group 1	85	14.84	2.581	.280	0	19
Group 2	116	14.98	2.273	.211	2	19
Group 3	142	15.51	1.753	.147	5	19
Total	343	15.17	2.175	.117	0	19

7.6.5.2 Individual item properties

The results of item discrimination, item-total correlation and alpha values for attitudinal items are presented in Table 31. In contrast to the knowledge and skill items, the other half of the sample (n=172) was selected to produce the

item discrimination index for the attitude items. Using their score on the 19 attitudinal items with a possible highest score of 19 (Strongly Agree and Agree were assigned a value of 1, Unsure, Disagree and Strongly Disagree were assigned a value of 0; the three negatively scored items were reverse-scored), results of the top 25% of high scorers (n=43) were compared with the bottom 25% of low scorers. High scorers scored between 16 and 19 on attitude items (M = 17, SD = 2.12). Low scorers scored between 8 and 15 on attitude items (M = 12.9, SD =1.73). In total, seven items received a score above 0.20 and were retained. Twelve items were candidates for deletion based on a discrimination index below 0.20. Three items showed a value below 0.20 for the item-total correlation, two of them reverse-scored items, and showed negative values. With only seven items above 0.20 for discrimination, Cronbach's alpha dropped from 0.77 on the original 19 items to 0.36 on the revised sample of seven items.

To ensure an acceptable alpha (0.70–0.80) (Nunnally, 1994; Polit & Yang, 2016), the decision was made to retain six items that scored below 0.20 for discrimination using 0.10 as the cut-off. Three of these items had low item-total correlations and these were excluded. Cronbach's alpha for the ten retained items was 0.80 and all item-total correlations were above 0.20. These 10 items were retained as the final item set for the PANA_Attitudes Questionnaire.

Table 31

Item characteristics PANA_Attitudes Questionnaire

no.	Item	Discrimination Index %	Item-total correlation	Alpha if item removed	Final Alpha
1.	A palliative approach can help a person's quality of life	17	.47	.76	.78
4.	Being aware of a person's emotional, social and spiritual needs is my responsibility	28	.39	.76	.79
6.	Caring for a person with a palliative approach is rewarding	14	.40	.76	.78
7.	Providing a palliative approach based on an individual's wishes improves quality of life	19	.45	.76	.78
10.	Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach	12	.65	.75	.77
11.	I feel comfortable when an individual receiving a palliative approach says they are ready to die	70	.28	.77	.81
13.	I make a difference to a person's day when I provide care with a palliative approach	21	.65	.75	.76
14.	I have an important role to play in pain assessment and management	33	.52	.75	.78
16.	When I provide care with a palliative approach, I think about the whole person	17	.61	.75	.77
17.	Privately sharing experiences with colleagues is important when providing a palliative approach	49	.40	.76	.79

Note: Items removed from the instrument are shown in Appendix 10.

7.6.6 Validity Results

7.6.6.1 Discriminative validity

To evaluate the discriminative capabilities of the PANA_Knowledge Questionnaire compared to the existing PCQN, a between-groups analysis and test of significance using ANOVA was performed. The value for statistical significance for the analysis was set at Cronbach's alpha <0.05. Groups of participants were asked to identify to which group they belonged: Group 1: less than two years' experience; Group 2: between two and five years' experience; Group 3: More than five years' experience. Item scores and mean scores between groups on both instruments were examined to test the following study-specific hypotheses: that an instrument designed for nursing assistants' level of education and scope of practice within a palliative approach

I. will perform better than the Palliative Care Quiz for Nursing (PCQN) (Ross et al., 1996) in discriminating knowledge of a palliative approach between groups of nursing assistants;
II. will demonstrate that experience measured as length of time in the nursing assistants' role is better than education in discriminating knowledge of a palliative approach between groups of nursing assistants;
III. will detect differences between groups of nursing assistants for knowledge of a palliative approach based on experience in the role;
IV. will detect differences between groups of nursing assistants in skills for a palliative approach based on experience in the role;

V. will detect differences between groups of nursing assistants for attitudes towards a palliative approach based on experience in the role.

A two-way ANOVA was performed on the final 17 items of the PANA_Knowledge Questionnaires with level of experience as the first factor and level of education as the second factor. The results are presented in Table 32. Descriptive statistics for the final knowledge items are shown in Appendix 12.

Table 32

Two-way ANOVA for knowledge scores: experience in role and level of education

Tests of Between-Subjects Effects

Dependent Variable: Total Knowledge

	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	98.343[a]	17	5.785	1.131	.322
Intercept	29813.909	1	29813.909	5829.862	.000
@What is the highest level of education you have completed	43.978	5	8.796	1.720	.129
@Please indicate how long you have been working in this role	24.440	2	12.220	2.390	.093
@What is the highest level of education you have completed* @Please indicate how long you have been working in this role	43.627	10	4.363	.853	.578
Error	1687.620	330	5.114		
Total	67305.000	348			
Corrected Total	1785.963	347			

Note: a. R Squared = .055 (Adjusted R Squared = .066)

Results in this model trend towards a statistical difference for experience in role as measured by the PANA_Knowledge Questionnaire ($F = 2,390$, $df = 2$, $\rho = 0.093$), but there is no statistical difference for the level of education or for the interaction of education and experience on total knowledge scores.

A two-way ANOVA was also performed on the PCQN to compare the instrument's performance with the PANA_Knowledge Questionnaire, The results showed no significant difference between groups of nursing assistants based on years or experience or level of education or the interaction of experience and education on total knowledge scores using the PCQN (see Table 33).

Table 33

Two-way ANOVA for PCQN scores: experience in role and level of education

Tests of Between-Subjects Effects

	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	211.177[a]	17	12.422	1.174	.284
Intercept	6285.356	1	6285.356	594.054	.000
@7. Please indicate how long you have been working in the role_A	7.910	2	3.955	.374	.688
@5. What is the highest level of education you have completed_A	50.124	5	10.025	.947	.450
Error	3258.777	308	10.580		
Total	17689.00	326			
Corrected Total	3469.954	325			

Note: a. R Squared = .061 (Adjusted R Squared = .009)

A one-way ANOVA was performed on the PANA_Skills questionnaire and the PANA_Attitudes Questionnaire; the results are shown in Tables 34 and 35 below and show that there was no significant difference between groups based on experience for skills scores. However there was a significant difference between groups for the attitudes scores, demonstrating that the PANA_Instrument Questionnaire was able to discriminate between groups based on experience ($F = 5.252$, $df = 2$, $\rho = 0.006$).

Table 34

One-way ANOVA for skills scores and experience in role

	Total Skills				
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	21.235	2	10.617	2.031	.133
Within Groups	1777.780	340	5.229		
Total	1799.015	342			

Table 35

One-way ANOVA for attitude scores and experience in role

	Total Attitudes				
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	24.241	2	12.121	5.252	.006
Within Group	784.616	340	2.308		
Total	808.857	342			

In summary:

- There was no significant difference between groups for knowledge scores as measured by the PCQN with either experience in role or level of education.
- Knowledge scores between groups of nursing assistants and experience in role trended towards significance on the PANA_Knowledge Questionnaire, F = 2.390, df = 2, ρ = .093.
- There was no statistical difference between groups for skills scores and

experience.

- There was a statistical difference between groups for attitudes scores and experience F = 5.252, df = 2, ρ = 0.006.

7.6.6.2 Divergent validity.

The prediction that there would be a divergent relationship between the PANA_Knowledge Questionnaire and the PCQN was supported by the results presented in Table 36.

A correlation coefficient using A Kendall's tau statistic specifying a one-tailed test (the hypothesis was directional) was performed on the PANA_Knowledge Questionnaire to establish whether there was convergence or divergence with the PCQN. Kendall's tau is a non-parametric statistical test that can be used when data is not normally distributed. As with other types of correlation statistics, this test examines the strength of the relationship between two variables. Kendall's tau is reported as providing a better estimate of the correlation than other correlation procedures when the data set is small or has a large number of tiered ranks (Field, 2009). A small correlation (r = .166) was observed between scores on the PANA_Knowledge Questionnaire and those on the PCQN, with a significance value of less than .001 (ρ <0.001). This value indicates that the probability of getting a correlation coefficient of this magnitude in the sample of 350 participants is very low and that there is little correlation between the two knowledge instruments based on this sample.

Table 36

Correlation between scores PANA_Knowledge Questionnaire and PCQN

			Score PANA_Knowledge Questionnaire	**Score PCQN**
Kendall's tau_b	Score PANA_Knowledge Questionnaire	Correlation Coefficient	1.000	.166
		Sig. (1-tailed)	–	.000
		N	348	343
	Score PCQN	Correlation Coefficient	.166	1.000
		Sig. (1-tailed)	.000	–
		N	348	343

7.6.6.3 Structural validity: Exploratory Factor Analysis

A principal components analysis was conducted on the finalised items of the current data set with oblique rotation (Direct Oblimin). The Kaiser-Meyer-Olkin test and the Barlett's test of sphericity were used to verify the sample's adequacy for the analysis. As well, the correlation matrix was examined to identify that there were correlations between variables >0.3 and that the data set was factorable. Components with loadings above 0.3 were extracted and the number for extraction determined by the accepted rules of eigenvalues over Kaiser's criterion of 1, the scree plot, and a parallel analysis. A pattern and structure matrix was generated for interpretation. While a principal component analysis does not strictly identify latent factors for the purposes of interpretation, the analysis reduces variables into clusters and provides conceptual representation of the data. The best solution for interpretation is

one in which the factors are represented by a distinct subscale of measured variables (Watson & Thompson, 2006). At least three to four measured variables per subscale are recommended, with loadings on each factor that do not overlap with all other factors, although it is acceptable for a measured variable to overlap with more than one factor/component (Nunnally & Bernstein, 1994; Watson & Thompson, 2006).

A principal component analysis was conducted on the full final item set of knowledge, skill and attitudes. This analysis presented in Appendix 11 showed that the unrotated first principal component accounted for only 14.2% of the variance. Following oblique rotation, 13 components had eigenvalues over Kaiser's criterion of 1, and in combination explained 58.7% of the variance. The scree plot and a parallel analysis were used to confirm five components that accounted for 36% of the variance. A minimum variance of 50% is recommended (DeVellis, 2012). The coefficient alpha for each subscale ranged from 0.79 to 0.43. Examination of the factor loadings and item content suggested that there was no well-defined subscale structure for all components. For this reason, as well as the following, items were not finalised as a total instrument: i) the minimal variance shown in the correlations of the knowledge items with all other variables ii) the inclusion of mixed variables iii) and problems with equivalence between variables.

Consequently, the PANA_Knowledge Questionnaire and PANA_Skills Questionnaire were maintained as separate indices of overall knowledge and skills and not as separately scored subscales. The PANA_Attitudes

Questionnaire with response options provided as ordinal variables was independently subjected to a factor analysis, detailed in section 7.6.6.4 below.

7.6.6.4 Factor analysis supporting divergent validity

To test that the new instrument was not measuring the same construct as the PCQN, it was hypothesised that there would be at least two distinct factors identified in a principal component analysis such that items from the PCQN would load on one factor and items from the PANA_Knowledge Questionnaires would load on a second factor. To complete this procedure a factor analysis was run on the PANA_Knowledge Questionnaire items and the PCQN to examine the factor structure. Both item sets were subjected to a joint factor analysis (Clark & Watson, 1995). The analysis was run on a sample of 337 responses rotated orthogonally to a simple structure using Varimax rotation. Two factors were specified for extraction. Fourteen of the 18 PANA items loaded on component 1 and 16 of the 20 PCQN items loaded on component 2 (see Appendix 11). This result differentiates the two knowledge item sets and demonstrates divergence.

7.6.6.5 Principal components analysis of attitudinal items

A principal components analysis with oblique rotation was conducted on the ten retained attitudinal items (1, 4, 6, 7, 10, 11, 13, 14, 16 and 17). Analysis was conducted on a sample of 343 following the exclusion of five cases with missing values. The Kaiser-Meyer-Olkin Measure of sampling adequacy was .861 (very good) (Field, 2009) and the Bartlett's Test of Sphericity χ^2 (21) = 914.139, ρ <0.001. The variables in the anti-image correlation ranged from .782 to .927.

The correlation matrix on the ten items was evaluated to determine the

adequacy of the correlations, and showed that all items except item 11 correlated ≥ .3 or above with more than three other items in the correlation matrix (range 2–9) indicating items correlated well with each other. The highest correlation was r = .540 and no item exceeded r = .8, indicating that there was no problem with multicollinearity (Field, 2009).

The scale mean and standard deviation for the total instrument are presented in Appendix 11. The mean of the communalities before extraction was .5987 (range .530–.766). Three components with eigenvalues greater than one accounted for 59.86 % of the variance; the first unrotated principal component accounted for 39.5% of the variance. The scree plot showed a possible point of inflexion at the second and fourth data point. A parallel analysis was conducted to confirm the number of factors to extract. The parallel analysis indicated three factors, but because of the few variables in the analysis, the decision was made to retain two components. The results of the unrotated and rotated eigenvalues, variance accounted for, scree plot, component, pattern and structure matrices are also shown in Appendix 11.

Two components made up the subscales of the PANA_Attitudes Questionnaire using a principal components analysis. The pattern matrix was used for interpretation as follows: Component 1 represented holistic care; Component 2 represented a palliative approach. Table 37 presents the rotated component loadings, communalities, eigenvalues, percentage of variance, and alpha values.

Table 37

Factor structure PANA_Attitudes Questionnaire

		Components		
	Attitude items	1	2	h^2
Component 1	Holistic care			
16	When I provide care with a palliative approach, I think about the whole person	**0.777**	-.025	0.608
14	I have an important role to play in pain assessment and management	**0.749**	-.074	0.577
10	Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach	**0.699**	.127	0.619
13	I make a difference to a person's day when I provide care with a palliative approach	**0.644**	0.245	0.610
11	I feel comfortable when an individual receiving a palliative approach says they are ready to die	**0.570**	-.137	0.741
17	Privately sharing experiences with colleagues is important when providing a palliative approach	**0.508**	-.097	0.530
4	Being aware of a person's emotional, social and spiritual needs is my responsibility	**0.503**	.069	0.323
Component 2	A palliative approach			
7	Providing a palliative approach based on an individual's wishes improves quality of life	**0.904**	-.075	
1	A palliative approach can help a person's quality of life	**0.768**	.078	
6	Caring for a person with a palliative approach is rewarding	**0.417**	.328	
	Eigenvalues	3.95	1.04	
	% of variance	39.475	10.365	
	Alpha	0.75	0.66	

Note: The overall Cronbach's alpha for the PANA_Attitudes Questionnaire was 0.80 with 0.75 and 0.66 for each subscale.

The correlations between the subscales (Holistic care and a palliative approach) of the PANA_Attitudes Questionnaire are shown below in Table 38. This correlation was .202, deemed significant at the 0.01 level.

Table 38

Pearson's product-moment correlation between subscales on the PANA_Attitudes Questionnaire

	Subscale 1 Holistic care	**Subscale 2 A palliative approach**
Subscale 1 Holistic care		
Pearson Correlation	1	.202**
Sig. (2-tailed)		.000
N	343	343
Subscale 2 A palliative approach		
Pearson Correlation	.202**	1
Sig. (2-tailed)	.000	
N	343	343

Note: ** Correlation is significant at the 0.01 level (2-tailed).

The corrected item-total correlation (see Table 39) showing the total score omitting that item indicated that all items were above 0.30 and none were candidates for deletion.

Table 39

PANA_Attitudes Questionnaire internal consistency

Component	Item number	Scale mean if item deleted	Cronbach's alpha if item deleted	Corrected item–total correlation
Holistic care (n=7) Cronbach's alpha = 0.75	16	25.2070	0.700	0.588
	14	25.4198	0.712	0.508
	10	25.3003	0.701	0.596
	13	25.3469	0.690	0.623
	11	26.3973	0.768	0.350
	17	25.6414	0.729	0.437
	4	25.3178	0.739	0.368
A palliative approach (n=3) Cronbach's alpha = 0.66	1	9.0204	0.573	0.448
	6	9.1254	0.660	0.391
	7	9.0845	0.418	0.561

7.6.7 Reliability Results

Internal consistency was assessed with Cronbach's alpha coefficient and test-retest reliability was assessed with a Pearson's product-moment correlation. The Pearson's correlation was performed on all original items (n=85) as well as on each separate item set.

Twenty participants completed the three questionnaires of the instrument at time 1; only 16 completed the instrument at time 2. One participant did not proceed to the PANA_Attitudes Questionnaire at time 2.

Five participants (25%) were from group 1, four (20%) from group 2 and

eleven (55%) from group 3. Three participants indicated they were between 25 and 34 years of age, six were between 35 and 44, five were between 45 and 54, and six were between 55 and 64.

Scores (n=20) on the original 28 knowledge items ranged from 21 to 27 (M = 23.60, SD = 1.87), suggesting some variability in knowledge about a palliative approach. At time 2, scores ranged from 20 to 26 (M = 24.12, SD = 1.54). The average difference between time 1 and time 2 was 3 weeks (25.58 days) (range 17–36 days). The Pearson's correlation value on the 28 knowledge items was r = 0.655**. On the final 17 knowledge items, the mean score at time 1 (n=20) was M =14.40, SD = 1.698, at time 2 (n=16), M = 14.75, SD = 1.390. The Pearson correlation value on the final 17 knowledge items was r = 0.735**. Both values were significant at the 0.01 level.

Scores (n=20) on the 38 original skill items ranged from 28 to 38 (M = 36.50, SD = 2.646) suggesting some variability in skill perception. At time 2, scores (n=16) ranged from 15 to 38 (M = 35.81, SD = 5.856). On the final 13 skill items, the mean score at time 1 (n=20) was M = 11.90, SD = 1.917, at time 2 (n=16), M = 12.00, SD = 2.394. The Pearson's correlation value for the 38 skill items was r = 0.0421. On the 13 final skills items, r = 0.608* which was significant at the 0.05 level.

Scores (n=20) on the 19 original attitudinal items ranged from 12 to 18 (M = 15.60, SD = 1.273) indicating variability in attitudes. At time 2, scores (n=15) ranged from 14 to 19 (M = 15.47, SD = 1.552). On the final 10 attitudinal items, the mean score at time 1 (n=20) was M = 9.30, SD = 1.081; at time 2 (n=15), M =

8.93, SD = .884. The Pearson correlation value for the 19 attitude items was r = 0.619*. On the final 10 attitude items, r = 0.619*. On both occasions, the value was significant at the 0.05 level. Table 40 provides a summary of the correlation scores for the 85 original items and the finalised items in the test-retest.

Table 40

Pearson's product-moment correlation for PANA_KSAq, PANA_Knowledge Questionnaire, PANA_Skills Questionnaire, PANA_Attitudes Questionnaire

Instrument	**Sample**	**Test-retest Pearson's correlation**
PANA_KSAq (n=85)	16	0.457
PANA_Knowledge Questionnaire (n=17)	16	0.735**
PANA_Skills Questionnaire (n=13)	16	0.608*
PANA_Attitudes Questionnaire (n=10)	15	0.619*

*. Correlation is significant at the 0.05 level (2-tailed **. Correlation is significant at the 0.01 level (2-tailed).

7.7 Chapter Summary

This analysis has resulted in an 85-item instrument being refined to i) a 17-item PANA_Knowledge Questionnaire with dichotomous items retained as a separate index of overall knowledge; ii) a 13-item PANA_Skills Questionnaire with dichotomous items retained as a separate index of skills; and iii) a 10-item PANA_Attitudes Questionnaire scored on a 5-point ordinal scale consisting of two subscales: holistic care and a palliative approach.

The PANA_Knowledge Questionnaire performed better than the PCQN in discriminating knowledge of a palliative approach between more and less

experienced staff. A principal component analysis confirmed the presence of two distinct factors across the two instruments, providing further evidence of the new instrument's discriminant validity for NAs in RACFs compared with the PCQN. The instrument demonstrated good internal consistency and in the test-retest outperformed the PCQN. In conclusion, the PANA_Knowledge Questionnaire is a psychometrically robust instrument that is able to discriminate between nursing assistants with different levels of knowledge of a palliative approach.

The 13-item PANA_Skills Questionnaire is an index of overall skill in the delivery of a palliative approach. The instrument indicates high internal consistency and compares favourably to palliative care practice as measured by the Palliative Care Survey (Thompson et al., 2011).

The 10-item PANA_Attitudes Questionnaire, scored on a 5-point ordinal scale demonstrates strong discriminative validity, demonstrated by its ability to detect a statistical difference between groups of nursing assistants based on experience in the role.

The PANA instruments were designed and developed to evaluate nursing assistants' knowledge, skills and attitudes and palliative approach. They have demonstrated preliminary evidence for acceptability, validity and reliability for nursing assistants' scope of practice.

Chapter 8 Discussion

8.1 Overview

This final chapter discusses the main findings of this study and some implications for research, education and practice for the continuing professional development of nursing assistants in RACFs. This is important because nursing assistants constitute 70% of the RACF workforce and provide most direct care to residents. The chapter outlines the significance of this study followed by the findings resulting from the study hypotheses. An appraisal of the mixed methods approach used in this study is considered. The last section of the chapter examines the strengths and limitations of this research and some recommendations for future research.

8.2 Significance of study

This study developed an instrument designed to elicit the educational needs of nursing assistants to enable them to deliver care with a palliative approach. This study was motivated by the lack of such an instrument for nursing assistants' scope of practice and consistent reporting of poor palliative care knowledge within this group (Ford & McInerney, 2011; Pfister, Markett, et al., 2013; Ronaldson et al., 2008; Unroe et al., 2015). When considering the palliative care needs of older people in RACFs, these findings are cause for concern and investigation.

This study is significant on three counts: first, it is the first Australian instrument developed specifically for the role of nursing assistants, and the first

worldwide to evaluate the three attributes of knowledge, skills and attitudes. Second, the PANA questionnaires are the first Australian-developed tools derived from the collective voices of nursing assistants working in a range of Australian profit and not-for-profit organisations. In this respect, the instrument reflects the unique industry knowledge and practices operating in Australian RACFs. Third, the three new PANA questionnaires are reliable tools for assessing gaps and current educational shortfalls that impact on nursing assistants' provision of palliative care in Australia. As such, they provide a means of evaluating the outcomes of both pre-service education and ongoing professional development of nursing assistants in Australian RACFs, with the potential for translation to an international setting.

8.3 Nursing Assistants' knowledge of a palliative approach

This study put forward the hypotheses that an instrument designed for nursing assistants' level of education and scope of practice would I) perform better than Ross et al.'s (1996) Palliative Care Quiz for Nurses in testing nursing assistants' knowledge of a palliative approach; II) show that experience, measured as length of time, in the nursing assistants' role is better than education in discriminating knowledge of a palliative approach between groups of nursing assistants; III) be able to detect differences in nursing assistants' knowledge based on experience; IV) be able to detect differences in nursing assistants' skills based on experience; and V) be able to detect differences in nursing assistants' attitudes based on experience.

The first major finding of this study is that nursing assistants demonstrated improved scores on the new PANA_Knowledge Questionnaire when compared with the PCQN. Moreover, the PANA_Knowledge Questionnaire demonstrated greater sensitivity than the PCQN for detecting differences in knowledge of a palliative approach by nursing assistants, with a trend towards a significant difference in the knowledge scores of nursing assistants based on experience. Taken together, these results provide support for the hypothesis that the PANA-Knowledge Questionnaire would perform better than the PCQN in assessing nursing assistants' knowledge of a palliative approach (Hypothesis 1).

A desirable quality of a knowledge instrument is that it can distinguish or discriminate between participants with specific characteristics pertaining to that knowledge. Unlike items in the PCQN (Ross, 1997), PANA Knowledge items satisfactorily tap into the knowledge of the sample and demonstrate a range of knowledge scores from low to high. This study shows that across the spectrum of experience, nursing assistants perform well when measured with an instrument designed for their level of education and scope of practice. This is in contrast to previous studies which have shown that nursing assistants have low overall knowledge of palliative care (Ford & McInerney, 2011; Pfister, Markett, et al., 2013; Ronaldson et al., 2008; Thompson et al., 2011), and reflects the instrument's specificity and sensitivity to the nursing assistants' role.

The final items of the PANA_Knowledge Questionnaire reflect on the philosophy and principles of a palliative approach, including to whom this approach applies. Items address physical symptoms, assessment and management, and,

importantly, pain management, appropriate to the level of education and scope of practice of nursing assistants. Support of families, social support, and end-of-life care are included to test knowledge of the deteriorating and terminal phases of a resident's life. Items are written in such a way as to provide a trigger for reflection about what the participant might need to do.

Knowledge scores across the sample when measured with the PCQN are low. This corresponds to previous Australian studies (Ford & McInerney, 2011; Ronaldson et al., 2008), which reported low mean scores for nursing assistants using the PCQN. It is worth noting that Ford and McInerney (2011) also stated that the scores of nursing assistants were similar to those of the ancillary staff, which suggests kitchen and cleaning staff, who were also included in their sample.

This study's results correspond to previous research on two counts. First, the significantly lower knowledge scores for nursing assistants measured with the PCQN are comparable to those of other, previously mentioned studies, and demonstrate that the development of a new, sensitive instrument appropriate for nursing assistants' level of education and scope of practice is a valid and reliable indicator of knowledge of a palliative approach. Secondly, levels of knowledge equate to experience in the role, also found in the study by Pfister, Markett, et al. (2013). The likely explanation for this correlation is that knowledge improves over time as a result of exposure to the setting and to the older person with palliative care needs.

The statistics for the PANA_ Knowledge Questionnaire support the conclusion

that it is a psychometrically robust instrument which is able to discriminate between nursing assistants with different levels of knowledge of a palliative approach. For this reason, the instrument is suitable for evaluation of this level of worker in RACFs.

8.4 Nursing assistants' skills in a palliative approach

The second major finding is that there was no significant difference in nursing assistants' skills across level of experience when evaluated with the new PANA_Skills Questionnaire; consequently, this hypothesis was not supported (Hypothesis 4). However, a significant difference was detected for skills scores across groups and the level of education (see Appendix 12). This indicates that level of education, rather than years of experience in the nursing assistant's role, translates into significantly higher palliative care skills.. These findings are within the context of a stable nursing assistant workforce within RACFs and relatively long tenure for many staff (Mavromaras et al., 2017). A major implication is that the skills of nursing assistants, across years of practice and experience, remains largely static when measured with a tailored instrument for their scope of practice. When palliative care education (such as programs developed by specialist palliative care teams) has been provided, new knowledge has been found to benefit nursing assistants' skills and practices within RACFs and to have a direct impact on quality of care (Cronfalk et al., 2015).

At 13 items, the PANA Skills Questionnaire satisfactorily taps into the skill set of the largest group of care providers who have historically returned significantly

lower total practice scores than other groups of RACF staff such as RNs, ENs, and social workers when bereavement, planning and intervention, and provider coordination are also evaluated (Thompson et al., 2011).

The final item set of the PANA_Skills Questionnaire reflects the difficulty many participants experienced with the item set, as evidenced by the variability of scores. Of these 13 items, one relates to each of the categories (generated in Phase 1) of documentation and observation, pain and symptom management, physical comfort, needs of families, team approach, social support, end-of-life care, and professional development and reflection. While several skill items present as generic in content, they are all applicable on a daily basis when caring for an older person with palliative care needs. Unlike many of the other instruments, they are also specific to the role of a nursing assistant and do not include the domains of nurses; for example, when compared with the self-efficacy items in the Bonn Palliative Care Knowledge Test (Pfister, Markett, et al., 2013), items such as convincing a doctor about the need for palliative care support, teaching the patient about possible side effects of prescribed medications, or counselling patients about how nausea can be alleviated, do not reflect what nursing assistants do. On the other hand, the ability to communicate, report and liaise effectively and observe changes are essential skills, but may not be sufficiently tailored to the palliative care needs of residents to impact on their quality of care (Australian Government Department of Education and Training, 2016c). The inclusion of items specifically related to pain observation and the use of reliable pain assessment tools in the skill set of nursing assistants, is an important implication for the delivery of quality

palliative care, with nursing assistants identified in previous studies as an untapped and untrained resource in palliative care provision (Dobbs, Baker, Carrion, Vongxaiburana, & Hyer, 2014; Holloway & McConigley, 2009; Jansen et al., 2017; Liu, 2014).

To date there is little to help assess nursing assistants' scope of practice and a palliative approach. The difficulty of designing an instrument that captures what staff actually do instead of what they are supposed to do, or think they do, has been acknowledged (Thompson et al., 2011). This study's results differ from other studies in which perceived skills and competency do not equate with experience as measured as time in role (Pfister, Markett, et al., 2013; Unroe et al., 2015). However, as this instrument is a self-report measure, it is difficult to gauge whether there is a difference between the skill of experienced and inexperienced staff, or whether inexperienced staff report, for example, knowing how to care for a person with challenging behaviours when in fact they do not. It is also speculated that inexperienced care providers may underestimate the physical and emotional demands of providing care with a palliative approach (Pfister, Markett, et al., 2013).

A new language is taking shape around the skills of nursing assistants in Australia. Skills previously described internationally as 'expert behaviours' and practices (McClement, Wowchuk, et al., 2009b; Unroe et al., 2015), are now articulated as 'clinical practice skills' (Martyn, 2016b). This indicates the expanded scope of practice of nursing assistants within the aged care workforce and emphasises the importance of their having formal education (reflecting

evidence-based knowledge and core competencies in knowledge) and the skills to deliver safe, high-quality care.

The development of nursing assistants' skills is needed to deliver care with a palliative approach, and this requires balancing the technical, professional and emotional aspects of care (L. Williams et al., 2016). Skills are needed to build competence and confidence in providing end-of-life care, particularly when 34% of all registered deaths occur in Australian RACFs (Australian Institute of Health and Welfare, 2016). Yet deficits in knowledge and confidence about this important aspect of care continue to be noted in the literature (Mager & Lange, 2016; Marshall et al., 2011; Unroe et al., 2015).

In this study, three of the twelve skill items pertain to end-of-life care (25%): recognition of dying, care provision, and self-care. The retention of these items was based on item discrimination and difficulty and, as such, they identify education and training deficits in end-of-life care in the study sample. All three aspects reflect identified challenges and deficits in the wider literature (Hohn, 2010; Nochomovitz et al., 2010; Unroe et al., 2015).

The essential skills and performance criteria detailed in *Deliver care services using a palliative approach* include the ability to monitor, evaluate and respond to pain, and the ability to implement strategies to promote comfort (Australian Government Department of Education and Training, 2016c). Three specific skill items related to pain and relevant to nursing assistants' scope of practice are included in the PANA_Skills Questionnaire. These items cover the clinical observation and evaluation of pain management strategies and the ability to

provide non-medication strategies such as gentle massage. As nursing assistants are the largest group of care providers in RACFs, no other worker is better placed to assist in meeting the unmet need for pain management in older people in RACFs (Hermans et al., 2016). This is not a new notion: training nursing assistants in pain assessment has been recommended in previous study findings, as well as education in gentle massage techniques to improve non-verbal communication and care of dying residents (Åhsberg & Carlsson, 2014; Holloway & McConigley, 2009).

The current skill items provide a valid and reliable cross section of skills essential for nursing assistants in providing care with a palliative approach to address the physical, psychological and emotional needs of residents. They also provide broad coverage of the performance criteria as outlined in *Deliver care services using a palliative approach*. The ability to identify one's own attitudes towards a palliative approach and end-of-life care, and reflect on one's own performance, is further incorporated into the evaluation of required knowledge and skills (Australian Government Department of Education and Training, 2016c). This study developed an attitudinal instrument because positive attitudes contribute to quality of care.

8.5 **Nursing assistants' attitudes towards a palliative approach**

The third major finding is that, when evaluated with the new PANA_Attitudes Questionnaire, a significant difference appears in nursing assistants 'attitudes relative to their experience in the role. Those participants who had been in the role for more than five years demonstrated significantly more positive attitudes

than those with less experience. This result supports the hypothesis that an instrument designed for nursing assistants' level of education and scope of practice within a palliative approach will detect differences in attitudes between groups based on experience in the role (Hypothesis 5).

Of interest, however, is that within the subset of the sample's descriptive statistics, (see Tukey's Post hoc test in Appendix 12), the most positive attitudes were from the least educated and most experienced staff and those with the least positive attitudes were from within Certificate IV in Aged Care/Group 1. This is an indication that within these subsets, those with the least education but with the longest tenure have the most positive attitudes. By comparison, those who had secured Certificate IV and had less than five years' experience in the role demonstrated the least positive attitudes. These results warrant a more focused analysis of attitudes, and of factors known to affect workplace attitudes such as affective state and workplace satisfaction, which are independent of education and experience.

Out of the original 19 attitudinal items, ten are included in the final instrument. When compared with other instruments designed to capture views and attitudes about palliative care and death and dying (see sections 2.4.3–2.4.6), the new instrument more specifically reflects the nursing assistants' role. The items illuminate the concerns and challenges faced by nursing assistants, and identify their unmet needs in education, training and support. For example, feeling comfortable when an individual says they are ready to die was a highly discriminating item in the PANA_Attitudes Questionnaire, indicating a wide

variation between participants who feel comfortable when their resident expresses a readiness to die and those who do not. This reflects the findings of Nochomovitz et al. (2010) in their use of the Comfort Scale. The difference is that the Comfort Scale focuses on symptoms, treatment and comfort in talking about death and being present at death, while the new instrument delineates both positive and negative attitudes in the context of the nursing assistants' role. Making a difference to a person's day and having an important role in pain assessment and management emphasises and recognises the value of nursing assistants. It is hoped that the inclusion of such items, reflective of content within performance standards, will positively motivate and empower them in their role.

The lack of psychosocial items in existing instruments has been identified as a gap (Pfister, Markett, et al., 2013). This gap reflects the challenge of providing psychosocial and spiritual care to older people in RACFs, especially those with dementia (Hermans et al., 2016). Bringing these important aspects of care into the assessment of nursing assistants' attitudes emphasises their key position in being able to identify a person's emotional, social and spiritual needs.

As well as identifying residents' needs, the need to acknowledge self-care needs and to support the intense emotional labour required in the daily working experience of nursing assistants is recognised (Thorne, 2015). The support of co-workers has been found to be an important element in preparing for a resident's death and managing loss and grief (van Riesenbeck et al., 2015). The PANA_Attitudes Questionnaire contains one item that taps into the nature of

supportive relationships with co-workers. Interestingly, this was a highly discriminating item (.49), indicating variability in responses. If nursing assistants do not choose, or are not able, to share experiences with colleagues, the question arises as to what they do to debrief when experiencing multiple losses, dealing with the challenges of family dynamics and the physical, psychological and emotional care needs of residents. Complementing the care needs of older people in RACFs is the need to support the care staff. If care is to improve across aged care services, creating opportunities for self-care, grief and bereavement support, and reflection on experiences should be included in workforce development initiatives for the whole support workforce (L. Williams et al., 2016)

Overall, the finalised items reflect important attitudes required for nursing assistants providing a palliative approach. These are necessary for the provision of psychosocial and spiritual care, acceptance of death and dying, pain management, and managing grief and loss.

8.6 Assessment of the effect of education and experience on nursing assistants capacity to deliver a palliative approach

The fourth major finding is that there were no significant differences in the interaction between level of education and experience for the attributes of knowledge and attitudes (see 2-way ANOVA in Appendix 12). These results (taken together with the finding that the PANA_Knowledge Questionnaire trended towards a significant difference in the knowledge scores of nursing assistants based on experience) support the hypothesis that experience

measured as length of time in the nursing assistant's role is a better indicator of knowledge of a palliative approach than education (Hypothesis 2). These results derive from a sample in which the majority of participants in Group 1 and Group 2 held Certificate III in Aged Care[7] (53.9% and 34.1 respectively), and the majority in Group 3 held Certificate IV in Aged Care[8] (39.3%) with Certificate III in Aged Care held by 29.7%.

It is understood that education alone does not change palliative care outcomes (Frey, Foster, et al., 2017; Mitchell et al., 2011), or practice development, or organisational culture (L. Williams et al., 2016). It does however, play an important part in enhancing knowledge, providing an evidence base for practice and fostering confidence, as well as skill development and competence to enhance clinical practices (J. Williams et al., 2016). Evaluation is part of this process.

If building competence through education and training in palliative care is to be achieved within the main component of RACF staff, that is, nursing assistants, the second finding of this study indicates that current education, including the educational unit *Deliver care service providing a palliative approach*, does not appear to confer greater knowledge. The reasons for this are likely to include the differences in nursing assistants' pre-service education and graduating attributes, as well as their lack of opportunities for professional development (Martyn, 2016a).

[7] Superseded in 2015 by the Certificate in Individual Support
[8] Superseded in 2015 by the Certificate in Ageing Support

This study's results show that years of experience in the nursing assistant's role was a better indicator of knowledge of a palliative approach and more positive attitudes than level of education. Skills scores were not significantly different across groups based on experience. These results were similar to findings by Ford and McInerney (2011) and Ronaldson, Hayes, Carey and Aggar (2008). However, the difference is that Ronaldson et al. (2008) found higher knowledge scores based on level of education whereas this study did not.

The study's findings are, however, contrary to those of Unroe et al. (2015), who found that years of experience in the role did not translate into higher palliative care practice scores as measured by the Palliative Care Survey. In fact, staff with less than six months' experience performed better on family communication than those with more than ten years' experience. Unroe et al.'s (2015) study highlighted low end-of-life knowledge scores across the 'nursing' RACF workforce inclusive of RNs, licenced practical nurses (EN equivalent) and nursing assistants, with this latter group returning the lowest scores for both knowledge and practice. While this is to be expected, considering nursing assistants are generally not educated beyond certificate level and have limited professional development opportunities (Martyn, 2016a), the authors make the case that education and training are stronger contributors to performance than years of experience in the RACF setting. Moreover, those staff who are most likely to benefit are those with the least education, specifically nursing assistants. This further supports the need for an instrument tailored to nursing assistants' scope of practice.

The wider implications of Unroe et al.'s (2015) findings for Australian RACFs is that the current configuration of less educated and skilled nursing assistants (70%) (Mavromaras et al., 2017) will yield lower quality palliative care. To redress this situation and improve palliative care knowledge, skills and attitudes in the level of worker that provides most of the care to residents, palliative care education and training must be provided systematically, with creditable and systematic evaluation processes.

While all three groups scored well overall, demonstrating knowledge of a palliative approach as detailed in the national guidelines (Australian Government Department of Health and Ageing, 2006), results did not show any significant difference in total scores regarding educational attainment. The conclusion that can be drawn from the results of this study's sample is that the instrument detected higher knowledge scores related to years on the job and not to educational attainment.

If education and training are, or should be, stronger contributors to performance than years in the nursing assistants' role, the results of this study make a case for rethinking the current education of nursing assistants. As discussed earlier, their education has been found to vary in content and not to be optimally aligned with the demands of the workplace (Martyn, 2016a). Education and training in palliative care has been identified by workers in aged care as one of the three most valuable areas of training (Deloitte Access Economics Pty Ltd, 2016; Mavromaras et al., 2017). This cannot be delivered on an ad hoc basis that results in some staff receiving education in palliative care

and some not.

It is clear from the study's results and from the literature that nursing assistants need to be supported in professional development opportunities to ensure they have the competence and confidence to offer high-quality palliative care. This is especially the case for staff with longer tenure and experience in the field, who comprised the majority of this study's testing sample.

8.7 Study Implications

8.7.1 Implications for research

The findings here provide insights for future research. First, what has emerged in developing the instrument is an identification of the gaps and current educational shortfalls in advancing nursing assistants' knowledge and skills; and, second, it reveals how nursing assistants feel about providing care with a palliative approach, determined by a specifically targeted range of questions. Evaluation of these targeted questionnaires can assist aged care providers to consider enhancing the skills and attitudes of this major group within the RACF workforce. The report commissioned by the Aged Care Guild on Australia's aged care sector acknowledges the 'rising levels of dependency' (Deloitte Access Economics, 2016, p. 3) in the RACF setting, the imperative for aged care providers to be responsive to consumer demands, and the opportunities and challenges relating to funding, sustainability and growth, and workforce and skills requirements.

To deliver quality aged care services in RACFs, future research could explore

the benefits to residents of improved skills training for nursing assistants: for example, training in systematic pain assessment. The best methods to implement targeted educational interventions around these identified needs should be explored. Improving the ways in which nursing assistants contribute to care, along with ways to develop awareness of residents' psychosocial and spiritual needs, would likely benefit residents and staff alike; and the capacity for nursing assistants to liaise more effectively with families and manage associated grief is an area for further research, particularly when considering the expectations and needs of families in this area and the frontline role of nursing assistants. As the training needs identified in this study are reflected in the international literature, research with international collaborators in the aged, palliative care research space could be a means to test the generalisability of the PANA tools.

Finally, considering the diversity of the RACF workforce, as well as the increasing diversity of residents, another area to consider is the cultural competence of the workforce in providing a palliative approach. This may require the examination of culturally specific backgrounds and their influences on attitudes towards a palliative approach, pain management, and dying and death: the areas that proved to be the most difficult and discriminating among this study's culturally heterogeneous sample.

8.7.2 Implications for education and practice

The RACF setting is a major provider of aged palliative care, evidenced by the high level care needs of older people being admitted and the number of deaths

within this setting (Australian Institute of Health and Welfare, 2016; Palliative Care Australia, 2014). For this reason, the main implication for practice is the competency of the RACF workforce to provide palliative care. This study provides evidence that nursing assistants, when evaluated with a tailored instrument designed for their level of education and scope of practice, demonstrate overall good knowledge of a palliative approach, but that differences between groups based on their experience can be detected when education is taken into account. While the most experienced staff performed significantly better, the level of education made no difference to total knowledge scores.

Development of palliative care competencies across RACFs requires additional, structured, education and training across the workforce, and ongoing professional development opportunities for nursing assistants, especially for those with the longest tenure. This is required because the PANA questionnaires identified deficits in the sample's knowledge of the philosophy and principles of a palliative approach, as well as deficits related to pain management. These are basic elements, outlined in the World Health Organisation's definition of palliative care (Sepulveda et al., 2002). Attitudes towards dying and death and the psychosocial aspects of care, also basic tenets of the palliative care philosophy, showed most variation within participants' responses, indicating the need for support and development of palliative care competencies.

Practice development is important because what has been found to matter most

to patients and families across palliative care settings relates to those providing care and how care is provided (Bainbridge & Hsien, 2016). This includes the circumstances around how care at the end of life is provided, and what preparation about impending death families have received. Bainbridge and Hsien (2016) identified the five indicators most associated with patients' quality of life reported by bereaved families. These were whether health professionals, including nursing assistants, provided the desired physical comfort and emotional support to the dying person, supported shared decision-making, treated the dying person with respect, attended to the emotional needs of the family, and provided coordinated care (p. 13). These are all areas identified in the PANA questionnaires.

As discussed previously, a number of skill and attitudinal items related to end-of-life care were found to be among the most discriminating and difficult for this study's sample. This study's findings correlate with the reported discomfort some nursing assistants experience in the context of dying residents, clearly highlighting a gap in education and training (Marshall et al., 2011; Nochomovitz et al., 2010). The PCQN (Ross et al. 1996) contains only one item relating to the last days of life, which is a science-based question on physiological and biochemical processes and the need for sedation. This is not suitable for nursing assistants' scope of practice. By comparison, the PANA questionnaires tap nursing assistants' knowledge, skills and attitudes on facets of end-of-life care with eight (20%) out of forty items.

As the projection for employment growth in the aged care industry is in nursing

assistants, ongoing education and training must delineate their needs from RNs and other health professionals working in the field. While interdisciplinary collaboration and working together in a team are important, the differences in educational preparation and training, differences in role requirements, and the amount of time spent attending to the physical, psychological and emotional needs of older people, require targeted education and training. An implication of these findings is that training and development is needed to address gaps in knowledge and skills, and to foster more positive attitudes to palliation, death and dying. Interventions to assist practice include opportunities for debriefing and reflection, support and education on grief and bereavement, and, very importantly, a supportive environment for nursing assistants in their care of dying and deceased residents.

A further implication for practice is the usefulness of the PANA instruments as viable tools to measure the core competencies of *Deliver care services using a palliative approach* within the certificates required by the industry. The PANA questionnaires align with this unit in respect to the following elements: applying a palliative approach; quality of life choices; advance care planning; end-of-life care; responsiveness to pain and other symptoms; and emotional and ethical issues (Australian Government Department of Education and Training, 2016c). The instrument could be used as a summative assessment and, potentially, as a tool for reflective learning. It could also be used across RACFs to demonstrate site-specific learning needs. As with other careers, building knowledge and skills over time leads to opportunities that enhance job satisfaction as well as in the provision of care. Raising the bar in education and

training for nursing assistants has the potential to transform this aged care workforce.

In all, training and development of nursing assistants within the RACF workforce is needed to ensure older people with palliative care needs receive the optimum quality of care. Significant growth is forecast for the aged care industry, and nursing assistants are the mainstay of the RACF workforce as fewer numbers of RNs work in these organisations. The emphasis on respecting consumer choices including comfort care and efforts to reduce the transfer of older people at the end of life to emergency departments, depends on a competent and confident RACF workforce able to meet the demands of palliative care provision.

8.7.3 Implications for implementation and administration

The PANA instruments can be implemented and administered in the following ways: i) at point of employability in an RACF to demonstrate the required knowledge, skills and attitudes of a palliative approach; ii) as evaluation tools within RACFs to evaluate the learning outcomes of current initiatives, including the residential aged care palliative approach toolkit (University of Queensland/Blue Care Research & Practice Development Centre, 2012); and iii) as discussion and reflection tools.

The PANA tools of 40 total items are each relatively short and straightforward to score, with the benefit and advantage of being able to evaluate specifically knowledge, or skills, or attitudes. The instrument can be delivered in paper or online format, as administered in this study, making its use practical for both

research and localised evaluation within the RACF setting.

8.8 Integration of data types in mixed methods

The sensitivity of the instrument for measuring nursing assistants' scope of practice, in encompassing the construct of a palliative approach, derives from the mixed methods approach of this study and the qualitative data generated in Phase 1. A number of key themes emerged which add value to the instrument design, and these findings are now discussed with reference to the qualitative data and the literature.

A palliative approach, as discussed in Chapter 3, is a construct of contemporary developed health care systems and institutions, with its foundational points in medical and nursing specialities and the biomedical model. For this reason, knowledge of a palliative approach is conditional, and founded in part on the transactions that derive from experiential knowledge (Bazeley, 2013). For nursing assistants, 'knowing the person' draws on these transactions and confers both lay and specialised knowledge. The lay knowledge interpreted as 'everyday knowing' (Cribb, 2009) is drawn from the daily high-level interactions nursing assistants have with the older person in the RACF. The specialised knowledge relates to the content of the *Guidelines* described previously in this study's methodology and conceptual framework. The qualitative data generated in Phase 1 provides evidence of these types of knowledge that nursing assistants have. Following are examples of data derived from the interview process in Phase 1.

8.8.1 'Knowing the person'

The final items in the instruments identify the complexity of discriminating between study participants and acknowledge other forms of knowledge as being important in practice. The value of 'everyday knowing', which draws on life experiences and relational knowledge, is a valuable form of knowledge connecting to the idea of personhood. In managing the complex physical, psychological, emotional and spiritual needs of residents, a deep level of knowledge, as well as multiple skills and empathy, is needed (Thorne, 2015).

Much of the verbatim qualitative data did not constitute final items, but deserves comment. The recurrent expression in the literature, and a theme in this study, is the importance of 'knowing the resident.' This 'knowing' endows staff with the right knowledge of what to do and what not to do in the context of individual residents, leading to the provision of individualised care (Waskiewich et al., 2012). Knowledge is inextricably linked to skill in practical and affective caring, in that caring pays attention to technical and personal factors, incorporates continuous, practical and moral judgements—and, importantly, is responsive to circumstances and to individuals (Cribb, 2009).

In responding to the interview question on what is essential knowledge when providing a palliative approach, one participant stated:

> You have to keep in mind the nature of the person you're approaching, their preferences, and to give them the best possible care. (participant 1, site 2)

As a participant contemplates individuals and their preferences, the knowledge

of what constitutes 'best care' for each one is derived, demonstrating important relational knowledge. An example of an item that reflects this sentiment and imparts meaning into measurement is

- When I provide care with a palliative approach, I think about the whole person.

Similarly, detecting changes based on this relational knowledge is described:

> They just don't know the terminology of that or they just don't know what's causing that but they know straightaway. But some of them, they've been here for 20 years, they've been pioneers in this [facility], so if a patient's colour[s] turns different or if the patient has a swollen arm, they know straight away, they tell the RN. They don't have to go to uni, but they just know straightaway because they've been taking care of that person, it's just continuity of care. (Participant 8, site 3)

An example of an item that reflects this sentiment is:

- Raise the concerns of (advocate for) the individuals in my care.

Augmenting the relational knowledge based on everyday experience, communicating important changes, contributing to solutions, having the ability to solve problems and liaise with other care personnel are clearly important skills for nursing assistants. These may be encompassed within the life skills and experiences that individuals bring to the role. If so, the importance of recognising these for role development and career progression is advocated, from theories of adult learning that incorporate one's own experiences in learning (L. Williams et al., 2016).

In part, the instrument reflects how to calibrate the human response to care. It integrates the common language of palliative care (assessment and management of pain, quality of life, dying and death) with data on human responses. In this respect, the integration of data types captures and translates meaning into measurement (Sandelowski, 2003).

8.9 Strengths and limitations of this study

8.9.1 Strengths of this study

There are a number of strengths to this study. First, the inclusion of nursing assistants was invaluable in informing the development of items, providing role-incumbent knowledge, and enhancing the relevancy of items; and, where possible, in directing the use of terminology. The involvement of nursing assistants as key research participants was generally well received and enabled the researcher to follow up with interviewees in Phase 1 and recruit a sufficiently large sample of participants for all phases of the study. Second, the sample size was a strength, large enough to enable the statistical procedure of factor analysis to examine the dimensionality of items (although the sample size for the test-retest was small). Third, the input of aged care experts from four professional and industry groups increased the validity of the instrument. Twelve experts reviewed the items for content. Several were based in rural and regional areas of NSW, countering the predominantly metropolitan-based sample of participants. Pre-testing the instrument was an invaluable component of the development process and allowed the researcher to evaluate the usability of the instrument in the practice setting.

Finally, all phases of the study addressed the gaps in the development processes of existing instruments to establish the validity and reliability of an instrument for the level of education and scope of practice of nursing assistants within a palliative approach.

8.9.2 Methodological strengths

Previous studies have consistently shown nursing assistants to have a low knowledge of palliative care when compared to nurses; however, none of the instruments critically evaluated in this study's literature review (section 2.4) were developed to assess the spectrum of knowledge—from poor to excellent—of nursing assistants. As demonstrated, nursing assistants have their own unique body of knowledge described as everyday knowing which is relational knowledge gained from the daily engagement with residents. Therefore, tailoring an instrument for nursing assistants needed to incorporate aspects of this knowledge. How they then transmit this knowledge to other care providers is important for optimising resident care. This is where skills and attitudes intersect with knowledge while reflecting the role, level of education and scope of practice of nursing assistants.

Key methodological issues in adapting and revalidating instruments for use in a new target group are identified by Ugalde et al. (2011), who report that statistical processes in themselves do not guarantee relevance. Their recommendations include tailoring instruments specifically to the target group. While the literature is important to augment theory, qualitative data collection that captures the attitudes of the target group—as well as delineates relevant

issues—is acknowledged as a limitation in the development of one of the instruments included in this study's literature review (see section 2.5.4) (Leclerc et al., 2014).

While existing instruments report moderate to good psychometric outcomes where validation information is provided (see Table 2), none of the research designs adopted all the standard psychometric processes for instrument development, including the qualitative evaluation of the target group conducted in Phase 1 of this study, face and content validation processes using experts, as done in Phase 2 (S-CVI = 0.99), and pilot testing in Phase 3 prior to larger scale field testing and a psychometric study in Phase 4 (DeVellis, 2013; DeVon et al., 2007; Lynn, 1986; Oppenheim, 2005). Standard indicators of translational and criterion (convergent, discriminant) validity, stability, and equivalence reliability are recommended to ensure the psychometric soundness of instruments (DeVon et al., 2007).

Methods to establish content validity beyond the .05 level of significance are proposed by Lynn (1986) and Lawshe (1975). Content validation as proposed by Lynn (1986) was adopted in this study in Phase 2. For reliability testing, two indicators were analysed: Cronbach's alpha to determine internal consistency, and a test-re-test to assess stability reliability. Only two of the instruments reported in the literature review included test-retest data (Phillips, Salamonson, et al., 2011; Ross et al., 1996).

Construct validity was examined in this study using three indicators to examine support for the study's first hypothesis. This was evaluated using an analysis of

variance between groups on knowledge of a palliative approach and knowledge of palliative care as measured by the PCQN, a Kendall's Tau correlation, and a Principal Components Analysis to evaluate the discriminant validity of the new instrument.

The rigorous approach undertaken in this study to develop the instrument exceeds development processes of all other relevant and reviewed instruments in this thesis.

8.9.3 Limitations that may affect the validity or generalisability of results

There are some limitations to the new instrument and the study sample. First, the sample development and testing took place within greater metropolitan Sydney, an area that does not necessarily reflect regional or rural nursing assistants' perspectives. The sample is, however, representative of an increasingly culturally diverse and overseas-born workforce that remains predominately female (Mavromaras et al., 2017; Negin et al., 2013). The evaluation tool is also skewed to an Australian context as it is generated from qualitative data, although the wider international literature was used within the conceptual framework of the *Guidelines* (2006) to confirm a priori themes in Phase 1 and to delineate content for item inclusion.

Second, participants who were familiar with and knowledgeable about palliation are likely to have self-selected potentially biasing results at several stages of development. This effect may have been counterbalanced by staff who were not knowledgeable or motivated by palliation, but who were participating

in response to encouragement from facility managers or educators.

Another limitation was that the questionnaires were presented in the same sequence in both the pilot and field tests, and were not counterbalanced for order effects. Although attrition was low (only 22 participants (6%) did not complete all questionnaires in the validation study), fatigue, or loss of motivation and interest may have forced unpremeditated responses from some participants.

While interviews have been used in this study to collect data, with participants self-reporting their knowledge, skills and attitudes, the researcher is aware that other approaches to data collection could have been adopted. For example, an ethnographic approach is an alternative and more reliable way of observing nursing assistants' skills and attitudes than a survey. This approach would have allowed the researcher to observe what nursing assistants actually do when they provide care, what their behaviours are, their spoken words and non-spoken gestures that indicate whether or not the core values of a palliative approach are in operation. 'Manufactured' data, such as the data generated from the interview questions in Phase 1, can affect participants' responses as they are cued to the researcher's interests; and responses may not accurately reflect what participants do in practice. However, as the aim of this research was to explore knowledge, skills and attitudes within a palliative approach, with exploration on the understanding of the philosophy and key principles, a verbal account by participants was deemed to be the most advantageous method of data collection. Silverman (2013) also reminds researchers of the importance of

subjective experience.

Finally, it is not possible to create an item pool within one manageable instrument that captures all elements with subtlety and still acknowledges the complexity adhering to scope of practice and cultural context. The instrument development process is the first step in a process of ongoing evaluation, review and refinement (DeVellis, 2012). Over time new items may need to be included to reflect further broadening in knowledge, skills and attitudes.

8.9.4 Participant engagement and researcher reflexivity.

Many valuable learning experiences were gained in the course of this research. Despite the challenge of lengthy data collection phases, the contribution of participants at various levels within the organisations who gave their time, support and assistance has left a positive imprint on this study.

Recording nursing assistants' responses to the interview questions prompted the researcher's own reflections on ageing, living with dementia, chronic illness and frailty, and life and death in residential aged care. One nursing assistant gave a particular insight into ageing from the perspective of youth: she was one of the youngest participants in the study:

> I think coming into a nursing home you realise so many things about life and aged care and old people. When you're younger you don't have knowledge about them [older people]. You'd think that they're normal, they're going to grow up at home, whatever, but when you come in here you see what they deal with when they're ageing. They go through so many things; sometimes they don't even remember their family. Like it's

> hard. I think it's a struggle. I don't like age. (Participant 10, site 3)

Another reflection, from an experienced nursing assistant, demonstrates an appreciation of life when viewing the RACF setting:

> When you work in a nursing home you appreciate your life, you look after your life differently to before. (Participant 9, site 3)

This comment suggests deep insight into the complex health and care needs of older people, discussed in the introduction of this thesis. Numerous comments underscored the presence of compassionate and caring individuals committed to providing the best possible care to older vulnerable residents. The comment by a male nursing assistant best encapsulates this stance:

> I've learned to be a better human being ... not to lose my patience more often. (Participant 1, site 2)

This articulation of self-awareness and empathy in the face of all the challenges of providing care has the essence of overriding as well as encompassing all other skills: 'learning to be a better human being' is one of the greatest testaments that can be brought to bear when caring for others.

8.10 **Recommendations for research**

Recommendations for further research based on the findings of this study include:

- Repeated use of this instrument on different samples of nursing assistants beyond the development sample to establish further the instrument's validity and reliability to support research findings.

- Use of the tools on point of entry to the RACF workforce and across RACFs to evaluate palliative care competence and identify training needs.
- Development of training strategies to improve the effectiveness of nursing assistants within the RACF workforce (e.g., pain assessment, training in the application of gentle massage) which, in turn, provides avenues for skill development and workforce opportunities.
- Wider evaluation of the RACF workforce especially in regional and rural areas, given the findings of this study.
- Exploration of the factors that contribute to positive attitudes within RACF staff.
- Finally, it is suggested that organisations are encouraged to support the professional development opportunities of nursing assistants as a high priority, to ensure that optimum palliative care is delivered to older people residing in RACFs.

8.11 **Conclusion**

The growth in the aged care industry reflects our ageing population and indicates the demand for aged care services. Older people with palliative care needs entering RACFs are highly dependent on skilled, compassionate nursing care. Whether a palliative approach is required on admission or at some later stage, nursing assistants will be involved in providing for their comfort and in caring for residents as they approach end-of-life care, and when they are actively dying. As nursing assistants are the largest aged care workforce and

provide most direct care in RACFs, their education and skill development within a palliative approach is a high priority for the sector and the community at large. The expectations of families are that symptoms will be managed and a comfortable and dignified death will be provided for their family member, even if the language, philosophy and principles of palliative care are not known. Therefore, there is an obligation by the industry and the government to guarantee the competence of the RACF workforce.

When evaluated with existing instruments, nursing assistants have been found to have a low knowledge of palliative care, and to display deficits in skills and attitudes. On critical examination, these instruments are found unsuitable for evaluating nursing assistants' scope of practice providing a palliative approach in RACFs. This study has developed three new PANA tools to evaluate specifically the knowledge, skills and attitudes of nursing assistants (see Appendix 13), developed using the validity and reliability criteria recommended by De Von and colleagues (2007) and Polit and Yang (2016). These questionnaires can be used for formative, summative and research purposes to determine learning and development across the population of nursing assistants. The *Guidelines for a palliative approach in residential aged care* (Australian Government Department of Health, 2006) provided the conceptual framework for the inclusion of content in this instrument. These first national guidelines provided the evidence base for resources designed to embed evidence-based practice for a palliative approach in RACFs across Australia. The PANA instruments are aligned with the performance criteria in the educational unit *Deliver care services using a palliative approach,* which is

offered in the nationally recognised aged care qualifications. This has implications for potential industry uptake of the instrument as an evaluation tool for formative and summative assessments of their staff to evaluate educational interventions.

The results of this study provide preliminary evidence for the acceptability, validity and reliability of the three new instruments in the context of strong growth in the aged care sector, increasing numbers of frail elderly residents, and a steady rise in the number of nursing assistants. Evaluation of this workforce's knowledge, skills and attitudes to provide quality palliative care for older people in RACFs is integral to nursing assistants' ongoing professional development.

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Appendices

Appendix 1 Publications

Karacsony, S. (2015). A critical review of instruments for nursing assistants' scope of practice and a palliative approach in long-term care settings. Short Communication. *Journal of Community & Public Health Nursing*. Accepted online 5 November 2015.

Karacsony, S., Chang, E., Johnson, A., Good, A. & Edenborough, M. (2015). Measuring nursing assistants' knowledge, skills and attitudes in a palliative approach. *Nurse Education Today, 35*(12), 1232-1239.

Appendix 2: Flyers

NURSING ASSISTANTS, PERSONAL CARE WORKERS

Invitation to participate

If you are a nursing assistant or personal care worker in a residential aged care facility (RACF), Sara Karacsony would welcome the opportunity to talk to you. Sara is a research student in the School of Nursing and Midwifery at the University of Western Sydney and has worked in palliative care for over ten years. Sara is developing a questionnaire to assess your learning needs in a palliative approach. This questionnaire will be a tool to assist aged care employers in planning goals for staff development to improve the quality of life for older people in RACFs.

The study has four phases and you are invited to participate in **Phase one.** This involves an interview with the researcher (approximately 30 minutes). These interviews will be taped but will be kept confidential so that you will not be identified.

If you are interested in participating in this study, please contact Sara Karacsony

email: 17208244@student.uws.edu.au (m): 0435078524

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is H9963

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.

NURSING ASSISTANTS, PERSONAL CARE WORKERS

Invitation to participate

If you are a nursing assistant or personal care worker in a residential aged care facility (RACF), you are invited to participate in a research study. The aim of the study is to develop a valid and reliable instrument to evaluate nursing assistants' knowledge, skills and attitudes in a palliative approach. An instrument that is sensitive to nursing assistants' scope of practice can identify learning needs for education and skills development. Such a tool will be useful in planning education and training, and evaluating the outcomes of interventions in a palliative approach for nursing assistants.

This study has four phases and you are invited to participate in **Phase three – Pilot testing**. This phase involves completing three questionnaires and answering a few general questions about you. Pilot testing will take approximately 30-40 minutes. Your feedback is extremely valuable in establishing the overall usability of the new questionnaire(s). The questionnaires are available online through Survey Monkey as well as in paper format.

The link to the online surveys is:

https://www.surveymonkey.com/s/PANA_Knowledge-Skills-Attitudes

If you have any questions about this study, please contact:

Sara Karacsony m: 0435 078 524

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Invitation to participate

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This study has four phases and you are invited to participate in **Phase four – field testing**. This phase involves completing four questionnaires and answering a few general questions about you. Field testing will take approximately 30 minutes. A small sub-group of participants will be asked to re-test the questionnaires a second time. Your feedback is extremely valuable in establishing the reliability and validity of the new questionnaires for use with nursing assistants. The questionnaires are available online through Survey Monkey as well as in paper format.

The link to the online survey is:
https://www.surveymonkey.com/r/PANA_Knowledge-Skills-Attitudes
If you have any questions about this study, please contact:
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Appendix 3 Participant Information Sheet (General)

Project Title: A questionnaire for assessing nursing assistants' knowledge, skills and attitudes in a palliative approach

Who is carrying out the study?

This research study is conducted by Sara Karacsony, a Higher Degree Research candidate at the School of Nursing and Midwifery, University of Western Sydney. This research will form the basis of the degree of a Master of Nursing (Honours). Sara will be working under the supervision of Professor Esther Chang, Dr Amanda Johnson, Dr Michel Edenborough and Dr Anthony Good from the University of Western Sydney.

All nursing assistants employed by the participating residential aged care facilities (RACFs) in Greater Western Sydney are invited to participate in this research.

What is the study about?

The aim of the study is to develop a valid and reliable questionnaire to assess nursing assistants' knowledge, skills and attitudes in a palliative approach. A questionnaire that is sensitive to the learning needs of nursing assistants can identify knowledge gaps for education and skills development. This questionnaire can be used as a tool to assist aged care providers in planning goals for staff development to improve the quality of life for older people in RACFs.

What does the study involve?

This study has four phases. You are being asked to participate in **phase one/two/three/four.**

Phase 1: Interviews with nursing assistants. Participants in this phase will discuss in a face-to-face interview with the researcher their perceptions of providing a palliative approach including what necessary knowledge, skills and attitudes enable them to deliver this care.

Phase 2: Expert advisory panel review. In this phase, experts from within the fields of aged care and palliation are invited to review question items for the developing questionnaire. This process provides validation of the content of items within the framework of a palliative approach. Participants are asked to rate questions for relevancy and acceptability, clarity and comprehensibility, and that the items cover the scope of a palliative approach. This process assists the researcher to identify and eliminate questions that are not relevant or do not add value and those that are poorly worded or difficult to understand.

Phase 3: Pilot testing. In this phase, three separate groups of nursing assistants will be asked to pilot test three draft questionnaires. Pilot testing allows the researcher to assess the overall usability of the questionnaires. The three groups include 1. Staff with less than two years' experience 2. Staff with experience between two and five years' 3. Staff with more than 5 years' experience.

Phase 4: Field testing. Participants in this final phase will be asked to complete four questionnaires either online using Survey Monkey or in paper format. A sub-group of participants will be asked to complete the questionnaires again approximately three weeks later. This phase is designed to test the reliability and validity of the new questionnaires for use with nursing assistants.

How much time will the study take?

i) Each interview will take approximately 30 minutes. The interview will be audiotaped ii) This process will take approximately one hour.

iii) Pilot testing will take approximately 30 minutes and will include completing three separate questionnaires as well as providing some general information. The questionnaires will be available for completion online as well as in paper format. iv) Field testing will take approximately 30 minutes and will include completing the questionnaires as well as providing some general information. Participants re-testing the questionnaires will require another 30 minutes.

Will the study benefit me?

The study will benefit you by providing an opportunity to contribute your important insights into a resource for nursing assistants and to reflect on your own knowledge and practice. Your reflection and participation will benefit your own practice.

Will the study involve any discomfort for me?

It is not expected that participating in this study will cause any discomfort. However, information on counselling services to support participants is included in this information sheet.

How is this study being paid for?

The expenses associated with this study are being covered by the candidate's research allowance.

Will anyone else know the results? How will the results be disseminated?

All aspects of the study, including results, will be confidential and only the researcher will have access to information on participants. The only other individuals who will review the de-identified data will be supervisors of the study. The results of the study may be presented in a journal article(s) and at a

conference(s) and will also be published in a thesis.

Can I withdraw from the study?

Participation is entirely voluntary: you are not obliged to be involved and—if you do participate— you can withdraw at any time without giving any reason and without any consequences. Consent will be required to participate in the study.

Can I tell other people about the study?

Yes, you can tell other people about the study and provide them with the researcher's contact details, to discuss participation in the study and to request a participant information sheet.

What if I require further information?

When you have read this information, Sara Karacsony will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Sara Karacsony on 0435 078 524 or, if not available, Professor Esther Chang at the University of Western Sydney on 9685 9046.

What if I have a complaint?

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is H9963.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you will be asked to sign the Participant Consent Form

Counselling Services for research study participants

In the event that study participants need support during or after participation in the study, Family and Community Services, NSW provides a list of general counselling and support services. Two of these provide 24 hour telephone support as follows.

Lifeline: 13 11 14

Lifeline offers a 24 hour crisis support service connects Australians with trained volunteers who can provide emotional support to anyone, anywhere, anytime. The telephone number for Lifeline is 13 11 14.

Salvo Care Line: 02 9331 6000

Trained counsellors at the Salvo Care Line are available 24 hours a day, 365 days a year. Our counsellors will offer a listening ear and help you work through a range of options which might include information and referrals to empower you to change your situation.

Human Research Ethics Committee
Office of Research Services

University of Western Sydney

Participant Consent Form

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Project Title: The development of an instrument to evaluate nursing assistants' knowledge, skills and attitudes in a palliative approach

I .....,consent to participate in the research project titled: The development of an instrument to evaluate nursing assistants' knowledge, skills and attitudes in a palliative approach

I acknowledge that:

I have read the participant information sheet [or where appropriate, 'have had read to me'] and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction. I consent to completing an interview.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

Signed:

Name:

Date:

Return Address: Sara Karacsony, c/o Professor Esther Chang, School of Nursing and Midwifery, University of Western Sydney, Parramatta Campus, Bid EB LG.r 12. Parramatta, NSW 2150

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The Approval number is: H9963

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Appendix 4 Interview Schedule For Phase One Data Collection

Date

Start time:

Stop time:

Venue:

Interview code:

Introductory question: What is your understanding of a palliative approach?

In your opinion, who provides a palliative approach?

Which residents do you think benefit from a palliative approach?

What are the greatest needs or important issues faced by the residents you care for?

What can nursing assistants do to improve quality of life?

What do you think is essential knowledge for a palliative approach?

What are the things that you know that can add to residents' quality of life?

What experience do you think is important?

What do you find the hardest part?

How do you think that your insights have changed over time?

What motivated you to do this type of work?

Do your caring experiences give you a positive feeling? Please explain.

Are there any aspects of your work that you find distressing?

What part of your role do you find most rewarding?

What skills did you bring to your role that have helped you?

Do you think that you have learned new skills?

How did these come about?

What specific skills do you think would be helpful for nursing assistants?

Appendix 5 Phase 1: Item Generation

Knowledge Categories

Category 1: A palliative approach	Question
101.2.2 A palliative approach to me is letting someone go comfortably, that's (pause) probably the best way to explain it 101.64 allowing a person to go peacefully, pain free and with dignity 101.27 Someone can go comfortably, pain free and with dignity ... 101.26.2 I mean to me, palliative means 'goodbye' go comfortable 102.6 but at the end of the day, it's all about trying to keep them happy and comfortable	1. The main aim of a palliative approach is enabling a person to die pain free and with dignity? 2. A palliative approach aims to improve quality of life?
103.2 I don't know, I don't know, which residents, don't a lot of them end up with palliative care, in the end anyway. We got two already that have been in palliative care for a long time, do you know what I mean. Doesn't mean they are palliative and it's going to end right away, I understand that; it can go for a long time, you're know, you're just keeping them comfortable 107.6 to make sure that they're comfortable, to make sure that their personal hygiene's kept up to date, things like that 305.10 palliative care, to give them good care, in the last [ ], keep them comfortable, that's what palliative care is, isn't it? 306.1 we approach people as the terminal stage of life ... aim to make them more comfortable, more secure in this life, in this stage	3. When a person receives palliative care it doesn't mean that they are actively dying? 4. A palliative approach is keeping a person comfortable throughout the course of their illness?

101.20 they say, 'OK, this person's palliative', OK, so, to me, my understanding is this person's no resus, none of this, none of that. Then all of a sudden that person goes downhill and the family comes in and goes, 'I want them to go to hospital'. I mean, they clash and you know full well, if that person goes to hospital, they gonna die in hospital, or they're gonna go to hospital, get a glucose drip and pick up until the next time, and it's just prolonging the inevitable	5. Sending a person to hospital when they become unwell prolongs the inevitable 6. Sending a person to hospital when they are receiving a palliative approach has the opposite intent?
305.2 Palliative care as far as the family's concerned is not to send to the hospital; it's people coming here to the nursing home and people who are in palliative care is, more, in the last stage 305.3 the hospital, I think the hospital ...], it's the family's concern too .. They don't want to send them to the hospital, to stay in the nursing home 305. 33 it's the family's choice not to send to the hospital to stay in the nursing home 305.65 sometimes is the family's wish not to send to the hospital. They just want them to—not to do anything when they die. Just leave them, let them go in peace. Some families, they want them to go to hospital	7. It is the family's decision to send their family member to hospital?
104.6 Just make them comfortable, and just do all the things that they need, as long as you can do them just make them feel comfortable so that they can achieve the best quality of life as possible	8. Making a person comfortable helps with their quality of life?
310.1 Meeting residents' needs. The normal shower care; changing; what a baby needs practically	9. The needs of a person receiving a palliative approach are the same needs as those of a baby?
102.1 A palliative approach to me is (..) at their end stages, and how we can make them feel comfortable. 103.1 The last stage in the person's life. Yeh, that's about it, isn't it 104.1 palliative is caring [for] residents at the last phase of their lives, palliative,	10. A palliative approach is intended for someone who is approaching the end stage of life? 11. A palliative approach is intended for people in the final stages of life?

making them comfortable and happy for the last stage of their life	
105.1 Just give them the most comforting care, relaxed care you can give because usually palliatives, to my understanding is the final stages in a lot of cases	
203.1 Palliative.. that's their last stage .. and palliative care, what we can do for them, actually. How can we look after them and their needs, not much though	
306.4 it's like final stage of life, a person who has, like, a severe disease	
301.17 palliative care is required for someone that is on their last stage of life and who needs, like, sometimes we have one on one nurses with them, just to care for them and doing everything for them cause they are not able to do themselves, more than other patients that we have	
302. 1 it means like someone is on the end stage of their life and how you care for that person. And the person and the family as well and how you respond with the person and the family with the resident	
302.3 the one who is at the end stage who needs palliative care.	
302.4 palliative care is you give a care to a patient whose at the end stage of their life	
304.1 Palliative approach is palliative care and that is when they're near the end, their dying, so they're under palliative care, where we know that there's not much longer for them	12. When people are dying, that's when they need a palliative approach?
307.1 Palliative approach what I understand is it's the end of life care—people who have terminal illness.. end of life care	
307.2 Final stages—his or her life	
308.1 Palliative care is about giving comfort to patient that's nearly dying—end of their life	
309.31 For palliative care is to the one—it's actually like an end of life for them. So	

they can't do anything else for them, just to make them comfortable. So that's about palliative care. Some of them they have morphine for pain. Some of them just being making comfortable	
206.1 a palliative approach is when a man or woman, a client is near to their death, doesn't matter, giving a particular time, this date or this time, but they're really near their end and they need special care. So, according to me, this is the special, everything, personal care, for food, for everything, according to that time of their need	13. There is no time frame with a palliative approach, it is the special care that is provided during this time?
305.7 the residents who are in the last stage, they are the residents who need palliative care	14. The people who need a palliative approach are those who are in the last stage of life?
305.37 it's the last stage of the patient, what we can do. Last stage, I meant to say, they are dying. So only thing we can do, to make them comfortable. As the last stage—that's the word I used. It was the last stage	15. Making a person comfortable in the last stage of life is the aim of a palliative approach?
203.4 who are the mostly sick and dying people 205.1 just taking care of them until they pass. Attending to every need	16. A palliative approach is taking care of people until they die and attending to their needs?
308.13 people think—if you say palliative, it's you're dying. That's what the notion—that's what they think. But if you actually learn behind that, you will actually give more—you can actually give more—pay attention to the family and to the patient—is actually in the palliative care	17. A palliative approach is not concerned with dying but is concerned with the person who is living with dying?
103.7 I never thought I knew what palliative was but now that I do, yeh, you know, it's just an everyday thing you do for the,, you're just caring for them and you don't just leave them there, you know, you just pay more attention and more care for them, than you would 205.5 Taking care of their everyday living, making sure they're comfortable and pain-	18. A palliative approach provides more attention to a person than everyday care? 19. Taking care of a person's activities of daily living means that they are comfortable and pain free?

free	
305.19 palliative care … is … to improve the quality care, giving them good care	20. A palliative approach aims to improve quality of care?
301.19 Basically someone that is going to go anytime soon; there's nothing else that we can do for that person. There's no medication that can cure whatever they have and it's just that path they're going to go; going to pass away or move on to the next life 103.24 for example someone got terminal cancer, so they're at that stage where there's no more treatment for it and it doesn't matter what medication you give them, they're not going to get any better, so we're just keeping them as comfortable as you can while they're here 202.29 no further treatment, it means they can't do anything 202.28 When sometimes they were sick and they went to hospital and the hospital people send them back, they say we can't do anything. So this is the time for people to stay in bed comfortably, like stay in bed, so that's the palliative care and the management they make that decision, this is her time, we can't do anything. So that's part of this palliative care. 202.27 suppose somebody pneumonia. So after that, when they come back they are not—some of the residents are not going to get better 309.68.2 Some of them down in palliative care which hospitals they can't do nothing about them. The doctor said there's nothing they can do about them too. So you are expecting them to go	21. A palliative approach is intended when no more treatment can cure the person's condition? 22. A palliative approach is intended when nothing else can be done for the person? 23. A palliative approach is offered when a person is not going to get better?
102.2 Uhm, terminally ill, uhm, MS patients do, cancer patients do, uhm, lung do, especially at their last stages of their emphysema and all that, eh, actually, yeh, mainly the terminally ill. When there's no going back 102.33 Well they're ones they've got cancer. They're ones they're just not able to	24. A palliative approach is intended for people with cancer? 25. A palliative approach is intended for people in

move, they're contracted up. Gee there's a lot	the last stages of their illness?
102.34 Just ones that are—you just know that they're going. I mean cancer's going to take you no matter what happens, there's no going back. It's not going to [dramatically] disappear or anything like that 304.6 Residents that have terminal cancers, maybe brain tumours and maybe, like, some who've had maybe amputations and aren't doing too crash hot 306.5 terminal disease, terminal, like the last stage of cancer, or heart disease, or kidney or liver 108.2 Uhm, dementia (Interviewer says: people with dementia?) 108.3 Yes, and people with cancer. (Pause) (Interviewer asks: any other groups of people?) 108.4 Some, heart disease. 201.22 they're mostly the ones that are really sick, like someone might be suffering from cancer in their last stage or with aspiration pneumonia 310.8 and like dementia and whatnot	26. People with dementia, people with cancer and people with heart disease all benefit from a palliative approach?
305.38 palliative care people are like—it's a chronic disease, that whatever—they are in last stage	27. A palliative approach is suitable for people with chronic late stage diseases?
104.2 those residents who can't do nothing much, like those who are immobile, and very sick patients, and whose got the diseases, very untreatable diseases. 106.2 the ones who can't walk, who stay in bed all the time and they get worse and worse, you know. That's the people 204.1 giving care to those persons who are staying on bed, who are not able to do	28. A palliative approach is intended for people who are no longer able to move? 29. The people who most benefit from a palliative approach stay in bed and are deteriorating? 30. A palliative approach can be offered to people

anything, so providing everything for them, helping them with feeding, personal care, changing their positions 204.3 Some are old, and some if they got any accident, if they are not able to move or if they've got back problem	who are old and frail?
106.11 they can't move, they can't help (sic). That's the hardest part, we need more nurses, we need three or four sometimes, They can't move at all, they got paralysed. Yeh, and they're having some diseases, like diabetes 202.35 sometimes somebody's leg—some diabetic person, the leg cut, so when we're handling him or her it's very hard, so that sort of people it's better to leave them in bed, so keep them in the bed side. Some, like, heart, where the heart is very weak, you're scared to be moving bed to chairs 202.1 they are very frail, they can't eat, they don't give up everything, so it means we just observing him or her. This is the time to be staying in bed; I think this is palliative situation. So we leave him or her in bed to look after. Two hourly turning, wash, personal care and mouth wash, something like this. All these things, you have to look after nicely, and keep him comfort[able] as palliative situations	31. In a palliative approach, people are best cared for in bed? (moved to attitudes)
310.2 The ones that have trouble with walking or looking after themselves, because there are some that do things on their own and others that don't and that's when we come in	32. The people who benefit most from a palliative approach are those people who are unable to do anything on their own? (moved to attitudes)
310.3 the greatest needs would be the normal looking after—the showering, the toileting rounds; the feeding; oral care; in general, care for them	33. Attending to the physical care of a person is the greatest need of a person requiring a palliative approach?
305.12 most of them under palliative care, are mostly bed-ridden 309.53 I mean the one that can't look after themselves I mean the one they're actually bed bound completely, they can't actually do anything, that's what we're	34. Most people receiving a palliative approach are confined to bed?

talking. Then the palliative care—they're only palliative care.	
311.2 the resident palliative—the ones they are in the beds palliatives, yeah. Feel sorry for them, they are still in bed, no response sometimes, while feeding them, it's very hard to feed them and just have to—you have to make them happy to give the food	
301.1 a palliative care kind of way is someone that requires full care. It can be someone that's on the last stage of life basically	35. A palliative approach is intended for a person with full care needs?
106.3 high care for everything, that's what I mean. For shower, watch them, keep an eye on them, their behaviours, to see the difference, like, the changes, those people	36. In a palliative approach, a person needs full care?
107.1 A palliative approach .. Oh, when they're not able to do anything.	
201.21 Because when someone is in a palliative care obviously they can't look after themselves that well because that's the stage that they're in	37. Only those people who are at the end of life benefit from a palliative approach?
107.2 a few, not a lot, not too much for palliative care, that would benefit from it really	38. Every resident should benefit from a palliative approach?
201.3 Every resident should benefit from it and especially the ones who are really, really sick and can't look after themselves really well	
202.31 Anyone that is resident there, so we have to care not only very frail but it depend if they are no more—sometimes you see they are not—maybe one week or two weeks	
303.4 all the residents would benefit, all the clients need palliative care and would benefit from the approach	
307.6 especially in the aged care team, it's all of them. All of them are involved—all of them	
308.6 everyone can benefit by a palliative approach. Everyone, yeah—any cultures.	

There's no discrimination in terms of palliative	
206.3 A few of the people they are not dying, but they are fighting with their lives, they are at the end and like they can't eat well, they can't walk, they can't do any movement, so those patients are more beneficiary from this palliative care because we giving them comfort according to their needs	39. People with advanced dementia benefit from a palliative approach even when they are not actively dying?
103.23 palliative care, the understanding of that is we don't have to force them, we don't have to bath them if they're not well that day. If they don't want to eat, I don't have to force them because if they don't want to eat, they have that choice. I'm not neglecting my duty of care by not feeding them—she's palliative, if she loses weight they know that she's going to lose weight ... When they're in palliative care, I don't say I'm not going to feed them, but if they don't have to eat, if they don't want to, they don't have to eat 202.32 They don't take any food	40. Forcing a person with dementia to eat or drink makes no difference to the course of their illness? 41. People receiving a palliative approach don't have to be encouraged to eat if they refuse food? 42. It's expected for a person with end-stage dementia to lose weight even if they continue to be offered food?
311.16 They can't eat nothing, so it's our responsibility to feed them, you know, and just to approach them like you have to eat, you have to—you know? Just make them happy	43. (One of the symptoms of end-stage dementia is that) a person eats and drinks less despite being fed? 44. It is a carer's responsibility to encourage a person to eat when they can no longer feed themselves?
309.4 Actually the ones that can't look after themselves at all ... The ones that can't look after themselves at all, they need more palliative approach than the ones that can actually look after themselves.	45. The people who can no longer look after themselves need a palliative approach more than those people who can look after themselves?
309.11 They're the ones who need more attention than anyone because they can't move, they're in pain, everything. So turning them, making sure they've got enough	46. The people who are full care and are being nursed in bed need more attention because

fluids, they don't get dehydrated. We know they are going but at least in that last minute, whatever they have, they need to be comfortable	they experience more pain?
105.2 when they're really getting to, it's hard for a nurse to, like everyday sort of care, for the families, everyday care ...when they're sort of getting at the end of their life's time. A lot of people put them on to, just before they decide, the families, to put a relative on to a peg feed 105.2.1 it's when it's getting towards that stage when they just need total help and getting to the end of their time	47. The decision to begin a palliative approach is when everyday care becomes hard for families? 48. The decision to begin a palliative approach is when a person is approaching the end of their life.
304.2 The doctors will put them under palliative care, the palliative approach .. we'll have palliative care nurses come into the facility... if they're on a certain injection, they'll do that for us.	49. Doctors and nurses decide when a person requires a palliative approach?
304.3 specialist palliative care nurses from the specialist palliative care units 304.4 RNs and the nurses can do, like, we get certain jobs we're allowed to do as well	50. Specialist palliative care health professionals support general primary care providers with advice and treatment? 51. RN and assistants in nursing provide a palliative approach?
104.3 personal needs, like hygiene feeding, and everything, uhm. I think that's the most important thing they need 106.1 When we do the palliative approach, like, we do more care for the people, like pressure area, oral regime, turn them every two hours, put some creams for the skins 204.4 Most important is positioning them, obviously if they stay long on one side, they're gonna feel pain 307.9 it's the repositioning when they are in the palliative care 107.3 Their personal care is their important one and their, uhm, some of them here are different nationalities as well, so we like to make sure their religion is very stand	52. The most important aspect of care is attending to personal care needs? 53. In a palliative approach repositioning, pressure area care and oral care are the most important? 54. Repositioning is the main aspect of care in a palliative approach? 55. Spiritual care is as important as physical care if the person receiving care says so?

out to them as well. Pretty much that's it 201.4 Their daily care needs, their daily showers, their personal care needs. Grooming, showering, toileting, and plus feeding and one to one talking, and, yes, spend time with them 202.30 comfortable is like personal hygiene, we have to do mouthwash, side to side change, put some cream on (sic)sore, bed sore. Also put booties, sometimes the heels are just (pause)… so all that sort of care, yeah, gently	56. Repositioning a person who is bedbound helps with pain management? 57. Frequent mouth care needs to be a part of daily palliative care?
202.2 They want comfort so everybody knows that this is the time	58. The time for a palliative approach is when everybody agrees that providing comfort is the goal of care?
201.1 You have to keep in mind the nature of the person you're approaching, their preferences, and to give them the best possible care	59. Giving a person the best possible care includes respecting the person's preferences and wishes
108.9 we can ask the family, the family member of them...so we can know the habits of the residents and help improve them	60. Asking the person's family about their habits and preferences helps to improve their care?
201.31 Some people they just don't want to live anymore I would say for any reason. I'd say—because we had this other lady, she was eating alright but all of a sudden she just stopped eating and there's nothing you can do because it's her wish	61. The reason while a person is receiving nutrition through a PEG is because of their illness? 62. Providing hydration and nutrition for a person through a PEG tube prolongs their life? 63. In a palliative approach a person can be offered comfort feeding even against medical advice if the person or family understand the risks of

	feeding? 64. Everyone involved in the care of a person with a life-limiting illness needs to be able to acknowledge an open attitude towards dying and death? 65. Being able to prepare for what is going to happen involves open discussion about death and dying? 66. Staff can get an idea about what a person's wishes are from reading their progress notes? 67. An older person can go without food or fluids for over 10 days if they are no longer able to drink?
103.6 I think you've got to encourage feeding even if they don't want to eat, you need to encourage the feeding, even if it takes longer, don't give up, just keep trying, you know what I mean, cause if they don't eat, don't drink, they're going to die.	68. It is an ethical dilemma for carers when a person decides to stop eating? 69. To prevent a person with dementia from dying it is important to encourage feeding?
101.3 the age group is getting younger 102.9 the people we get in now and how they've got the alcohol dementia and the drug dementia, so these baby boomers, what they said years ago is actually really happening 106.4 having some of them like ?mentals condition, which is behaviour, sometimes it's gonna be ok, gonna be changed, in the morning different in the afternoon, different in the night time. Yeh, that's why it comes care about the people. And, sometimes, they're running, like those people, they don't want to stay here	70. The age group of people with palliative care needs is getting younger? 71. People with dementia have the same symptom issues as people dying from cancer? 72. Routine is important for people with dementia? 73. Korsakoff's syndrome (or alcohol-related) is a common form of dementia in older people?

101.9.2 I have a bit of an understanding of why they're here 101.29 being in a dementia ward, now we've got six, seven smokers. Their life rotates around when they can get their cigarette, so, they know when, I mean, they've got dementia but they still know when it's time for a smoke 106.5 those people used to drink too much which is put them on the red alert. We have to look after them. And, the conversation, always talking with those people, communication ... they need that. Cause, they're missing that one. Yes, they need it 101.29.2 they change their routine, that resident's upset for the rest of the day, you know 101.30 familiarity, especially in dementia, familiarity 101.49 The age of these people coming in here with [Korsakoff's] or alcohol or you know [crumbs], they're all getting younger 101.60 some of these guys can't walk; we've got one in there who's having trouble: he can't, I can't walk him no more but he can weight bear, so when I'm showering him, I'll get him to stand there until his legs start to shake, that way he won't loose his muscles .. And, when I'm dressing him, he can stand up, that way his legs are getting a work out, sit down, stand up. 102.13 I didn't approach him the way I should really have approached him, but because he'd already been biting and carrying on, I should have backed this way but I didn't, I went that way 301.40 a lot of them have been like that, like there's nothing that they do on their own. Everything we do for them. So, with my understanding 301.44 usually dementia goes back to when they were younger or back when they were married having kids. So it's just having them doing things that they done when they were married or in their childhood. I think it keeps their mind working.	74. Resistive behaviours may be related to distressing symptoms such as pain?

301.49 Then you can understand more what kind of person they are and what to expect. Sometimes they don't mean to say or do something, it's the condition that they have, that's why they're doing it. You have to think these people are here for a reason, they're not just here because they want to be here. They're here because they're sick. So to not put their experience and what's happening to them now together	75. A person with dementia is admitted to a RACF and/or to hospital because they have developed advanced symptoms of the disease?
301.41 I think that it's just the immune system has gone down so low that they don't—they are so weak they can't do anything on their own and I think because they're just getting ready for that last stage of life I guess.	76. When a person can no longer do anything on their own, it is generally a sign that they are approaching the end of their life?
305.21 everyone individually is different, some of them are with it, some of them have dementia ... if you are good, you can do everything, once you have dementia, you just lose everything, you don't know anything, you don't feel anything once you have dementia you don't know what you're doing	77. Once a person develops dementia they don't feel anything or know what they are doing?
206.8 infection control, personal care, bowel care, personal hygiene care, such as oral care. Personal hygiene care for them, toileting, showering, everything including the quality of their life. If they are infection free from these things, and bowel maintained everyday and good shower, then they don't get a chance to get infection from anything or anything like that	78. Infection in people with dementia is likely to be caused by incontinence and/or nutritional problems?
101.60.2 a lot of them could wash themselves and do a half decent job and feed themselves and such and such. Go back a couple of months later and because you get a staff member who goes, 'oh bugger, it's quicker for me to just do it', they loose the ability 301.7.2 It gets them moving as well, having exercises so that their body is still moving and manage to do things and also their independence, always have that or try to have that 309.47.2 If they don't move their muscle, what happens? Contracts. After they're going to be stiff. So even if they still can feel to urinate, it's best to take them so they	79. Even though it's quicker to provide care, helping a person to do the things they were once able to do can help them feel in control of their lives?

can urinate	
202.12 Their aggressive behaviour, but we don't mind. That's why they're here. If they're normal they won't be like that	80. Aggressive behaviour in people with dementia is a reason for admission to RACFs?
310.15 Some residents that could be rude; that won't accept your care, yeah, because it's your job but sometimes they don't accept it because they don't know who you are	81. Resistive behaviours indicate the a person with dementia needs a palliative approach?
202.4 Sometimes they are very resistive or they can't eat properly	82. People needing palliative care can be resistive and unable to eat properly?
202.5 Some are OK, they can eat. Eating and turning positions, you know, just moving, but some are they don't do anything so we do everything... comfort in bed, rather then getting up and they are in pain	83. There is no single way of providing care for people receiving a palliative approach?
108.6 I think we need to know what they really want, we need to ask them sometime 303.21 If the resident is verbal and is able to tell you what their needs are, then I think as nurses and as an aged care provider we have to provide them with all the comfort we can give them. And, if they are not verbal, like it happens in this situation, we should just make it comfortable for them 108.7 I think communication, that's the most important thing. And, we need to follow the policy of the facility 204.4 Sometimes, they are not able to tell you whether they are hungry or not. It's up to the person whose providing the care, they should have to know their feeding time, or they're thirsty or whenever they've got [to be] changed	84. To understand what a person needs, it is best to ask them? 85. It is important to always ask the person's views concerning their care? 86. Communicating effectively with a person helps in understanding their needs? 87. When a person is not able to tell you whether they are hungry or not, offering comfort feeding (when appropriate) is part of a palliative approach?
106.8 What they've got, like if they're having any disease, and how many times we have to turn them, as an assistant in nursing, I'm not going to .. uhm, I need to know how many times I need to put the cream on the body, and how many times I need to watch them or not, yeh, and shower them or not, as some of them are having	88. It is most important to pay attention to repositioning and skin care when palliating a person?

problems with the skin and whether they need to have the water on it. And, if there is something that's changed, we ask the RN	
206.3.2 If they can't swallow and they don't want food, then we can't push them because they are already in the pain and if they are all the time in the bed, so to save them from the bed sores, we are turning every two hours or every hour to make them comfort	89. In a palliative approach, it may not be necessary for frequent repositioning? 90. When a person begin to have eating or swallowing problems, pushing food increases their discomfort?
206.4 every patient is different from each other, like, for example, my physical needs is different from her and her from you, so same like the clients, they are different from each other so every client, they have a different palliative care needs from each other 203.6 We are the ones who all the time are looking after them. I think their needs are ... more care and more . because we are always with them and we know their character and everything and every needs. ..different patients have different needs and we are the ones, at that time, understanding them 203.8 The residents like different kinds of things ... some likes music, some ... like playing with the dolls and they like sometimes to make up themselves and nicely dressed like they used to do in their previous life.	91. Care that is individualised is best able to address the holistic needs of the person receiving care?
105.8 just take a bit more care, you know they may need more talking to, they might need just a bit more reassurance. Maybe, a bit more study, you know, through the nursing home itself as part of our education. Just give us what's a good way to go: don't go down this road, but go down this road, just prepare us a little bit better	92. Reassurance through communication, understanding and empathy is the key to improved relationships?
102.37 Because they've usually got something wrong more than just dementia some of them. They get some cancers or there's other things wrong with them. They've just lost their mind. When they come in to us they've usually come in to us for a reason before they lose their mind. The alcoholics and the drug ones that we've got in there, their liver starts to go, their kidneys start to go ... so that's how we know that they're	93. People with dementia often have other long-term illnesses that affect their health? 94. It is difficult to understand how much the

going to get sick. Especially when their kidneys and that fail. .. When they go into renal that's quite bad for them 301.43 Different health conditions because a lot of them they don't just have one thing wrong with them there's a thousand things wrong with them. 102.36 [dementia] they don't know, but we know. They've got no idea what's happening to them. All they know is that something's wrong. I'm sure that something must be still up there, I'm not sure. But I don't know, you've just got to give them a bit more attention I think. 203.10 they are aggressive but same thing, we are just telling them and I understand their dementia but we are a bit out of things too	person with dementia understands?
206.9 if they're on the palliative care, then we need to read more knowledge on which condition is he or she, what's his basic needs and what we should do with our best quality for anything like showering, feeding, transferring, medication 304.24 We get a limited amount when a new palliative patient, if we get a palliative patient, comes in. We get the knowledge that they're a palliative patient and some of their conditions and if the nurses sit there and read the progress notes and the discharge letters from the hospitals, we're able to find out a lot more on what the resident's capabilities are and what the hospital or even the doctors have recommended for personal care	
304.10 knowing what the residents are going to need; uhm, what their conditions are ... if we've got a timeframe for them, and to make sure we've got the information there that we need to pull out all those programs together	95. Knowing what a person is going to need as their condition worsens can improve their quality of life?
304.23 Information on what their symptoms are to what we need to do, and especially knowledge 304.25 I read especially the discharge letters from the hospital as it gives us a bit of a background on how the resident ended up on, under palliative care and what their	96. Identifying symptoms is the first step in being able to manage symptoms?

symptoms are going to be and what, what's an alternative of what we can do for them 304.26 Understanding symptoms is important	
201.6 I would think essential knowledge is you have to put yourself in their shoes to see what kind of care they need	97. Understanding what a person is going through helps with providing care?
305.47 sometimes I want them to just stay in bed. But if it's [our side] that you can take them out in the water chair, or something like that. Move out from the room instead of just staying in bed 305.52 palliative care is chronic, I guess, for long term. But if you know that you are dying, there's—for my knowledge I don't—as I told you before, the patients are normally in bed, lying down. The only thing we have to do, change them and reposition them in bed and things like that	98. In a palliative approach, it is time for a person to remain in bed? 99. For people who are dying physical comfort care is the only requirement?
201.37 If someone can't look after themself very well, they can't attend their personal needs. Say they've been to the toilet but they can't clean themself very well, you help them. That's an improvement because the person can no longer attend to their personal care by themself anymore. So you try to do, make them clean	100. Quality of life can be improved by enabling a person to be clean and comfortable?
304.11 the information we get from their family members ... If they turn around and say they're able to feed themselves ..we're able to put that into a program .. we can try to prompt this person more to try to get them to keep their quality of life. .. if we're able to get them to do some of the work, it puts them in to, say, OK, we can do this sort of stuff, like, get them to wash themselves and get them to keep that quality.	101. Communication with families can encourage and enable people in the things they can still do?
202.50 Quality of life, because we have to give them—look after them look after properly, dignity, because we are—just like if we suppose going to somewhere in store we want best service from them	102. Providing dignified care helps with a person's quality of life?
304.8 They've got to be comfortable especially if it's their last days ... they're terminally ill where we know that they're going to pass away cause they're under palliative care	103. When death is close, the person's comfort is the overriding concern?

307.29 Providing privacy and dignity to the residents. Always keep in mind—whenever you attend the residents, put the curtains. Even with personal care, always put the curtains and things around 307.21 privacy and confidentiality among the families and the resident—any problems, … regarding the resident, we only deal it with the next of kin—the resident's next of kin and not to the whole family.. We talk to them confidentially	104. Dignity conservation includes factors such as privacy and asking permission to provide care?
308.1.2 Give them dignity and privacy as well—most of all comfort to them 308.49 One of my patients here, they don't talk, they don't say anything, but I still explain [to] them the purpose of my care, I explain why I'm there, whatever, that explanation for them, is not important for the others, but for that patient is important. That's already privacy, if you just come in and just (…) hold them, that's already privacy, what do you call that thing, uhm, invasion of privacy, cause whatever you do to a patient, you have to explain the procedure of care so they will understand what you're doing to them, even though they're not responding	105. It is important to explain the purpose of your care even when the person is not responding because this helps to maintain a person's dignity? 106. Promoting a person's dignity helps the individual feel valued?

Category 2: Physical symptoms – Assessment and Management	Question
101.34 the one that passed just recently, uhm, he was, he was crook, he had the flu and we were jumping up and down for a week, 'he's sick, he's sick, he's sick'. 'Oh, no, he's just sunstroke' he goes out in the sun yesterday, on Sunday, he's got sunburnt, well again he shouldn't have been out there that long getting sunburnt. But then, we're saying, 'he's sick, he's sick, he's sick', and 'no, he's not', and I was going off, [??] insist it's just heat stroke. 101.51 moments of clarity, they can be as sick as a dog with the flu or with pneumonia, you know, they'll tell you, and you'll just see it, see it, if you know your resident, that's the key, I think, know your resident that's when you see the clarity. 102.7 you need to know the resident, uhm, and if you don't, uhm, you work in one of these units of course, you don't, just, you know, holding their hands after them, and, basically, just knowing what stages there at, because they can actually last seven days, sometimes ten to fourteen days before they go in some of these units and I think that's a long time 102.31 we've got XX in there at the moment, he's been not eating or drinking and he'll say—he always calls me Mum, a lot of them call me Mum .. he goes, Mum I'm just tired. You know, so he just wants to be left. So we don't force him. We're not forcing him to eat or drink. We've put him on a food chart. We see how many times he opens his bowels, how he urinates, he's got a catheter anyway so we can see how much of the output; so he's still drinking but he's not eating. He's on thickened fluids too so he's actually still holding a lot of that down. I just know because I know what they are like before. But if I go into a palliative care unit and I wouldn't know, I would just have to rely on what I've read sort of thing. And let the doctors let us know. So that's how I can	1. Personal carers are likely to be the first to detect changes in a person's condition? 2. Even if a person is no longer eating or drinking, survival can extend beyond a week? 3. For a person who is no longer eating or drinking, it is still important to monitor their bladder and bowel function?

relate, but I know with XX he's given up 301.6. .. just to be aware of what you're supposed to do and what you're not supposed to do and the different conditions that the patient has as well, to be aware of that ... cause a lot of patients in palliative care are really weak, or whatever, and what their different conditions are, just to know the different conditions the patient has so you have your careplan and all that set for that need, that special need in that person	
307.18 when we know their illness, we can do the advanced care directives. We know what they want, what they are expecting when it's their end of life so that we can follow and provide support for them	4. When we know the person's illness, Advance Care Directives can be completed?
202.21 sometime is handover time, like handover report, we sometimes give my view sometimes, like residents is not sleeping and is better to put in bed one hour nap, some sort of things, and they say, right, oh OK	5. Not being able to sleep or stay asleep is a common symptom and cause of distress?
108.8 we need to know the knowledge about the disease of the residents, how to control, for example, we need to know infection control 204.6 About their body structure, and what problem they've got ..... and their special need, if somebody have any special need. 204.8 If we know the body structure, all the problems, what they're facing, what they're suffering from, it will be good for us to give better care to them. And why they're on bed	6. Having knowledge about disease helps to improve care?
102.23 I don't know why I know that they don't want to be alone, I mean they're quite sick. But you just know that when they give you that little bit of response—they sort of	7. Providing care to a person is improved when you recognise their needs? 8. People who are approaching the end of life

hold your hand a little bit more than they used to and you just know that they just need that tender loving care. And the drugs and everything else helps with it.	don't want to be left alone?
102.5 Well, I think you've got to look at the big picture, uhm, the families, as well as the resident, the patient, and how they would cope with everything. If you've known them for a long time, if you've worked in a nursing home, and they've been here for a long time, you exactly know how to deal with that person, you know, at their end stages. 104.16 When you get in touch with them regularly .. everyday and handling them most of the time, the same residents most of the time .. I know them very well. I know what they need and what they don't	9. You know exactly how to deal with a person if you have been providing care for a long time?
105.6 understanding a bit of their background would help. A bit more knowledge on what they've gone through to be at this stage 105.6.2 their personal history that can give us a better understanding of why they're here, why they're on palliative	
203.23 when you're attending them, you have to look through everything, like, the different signs of things, you know, like bruises	10. Regular assessments improve symptom management and a person's quality of life?
308.35 I think assessing the patient is one of that 308.39 it's physically the colours of the patient, the breathing—physically. That's how we assess them. That's—we actually tell the sisters—the RN in charge. Straight away we have to tell them—inform them so the doctors will come and check the patient 308.79 They just don't know the terminology of that or they just don't know what's causing that but they know straightaway. But some of them they've been here for 20	11. Observing physical changes in a person can be the first step in managing symptoms? 12. Assessment tools can provide more accurate information on symptoms than observation?

years ... so if a patient's colour[s] turn different or if the patient swollen arm, they know straight away, they tell the RN	
309.72—always not talk and not laugh and everything you might—or sort of suspect that they are going in a bit of depression but it would be helpful if you have education on that.	13. A symptom of depression is not engaging in conversation?
308.75 I know my residents very well because they give us this specific area now, so if there's any changes, you know straight away, if the patient's hallucinating or if the patient's, there's behaviour change, we know straight away that there's something wrong with them. And maybe they have UTI, constipated, you know, you tell it to the RN straight away .. you report it straight away so they can take some action 308.76 if the patient is behaving very well and there's a sudden change the following day, I'd tell the RN. The RN would tell me can you please check the urine, you do a UA, or can you please check the bowel chart, maybe she's constipated, you know those things. So, we do that, we actually communicate, so after that they will call a doctor or they will do something or they will assess something or they will give medication just to get rid of that constipation	14. A change in behaviour may indicate that a person has developed an infection? 15. Attention to bowel symptoms is important because constipation is a common problem for people receiving a palliative approach?
101.32 give panadol, panadol, panadol, so, a lot of the times, that's not sufficient 102.41 It takes a bit of the pain away at first. Then you need more. It takes the edge off things. .. So I really think that it does take the edge off it. But then it gets—you get used to—so then you want more. So I think that by giving them more that means that they're (pause) it's taking that edge off. 102.42 … they just look comfortable. They look relaxed, they're not in any pain. You can't see any physical pain on their faces or anything like that. .. when you touch them	16. Providing panadol for pain is usually sufficient for a person's pain management? 17. Morphine will need to be increased to keep a person comfortable? 18. Once morphine (or equivalent) is started, a person will get used to it and need more? 19. Providing pain relief before providing care helps a person relax when care is being

too much they do. But I don't know, it just seems that it puts them at ease. I think it puts them in peace 102.32 they'll get into a position all the time, they get comfortable they don't want you to touch them. But we have to encourage him that we have to turn you mate, otherwise you're going to get too sore being on one side and you'll stiffen up more .. Other than that, it's just the attention that they need, first I think they need the pain relief	provided? 20. Pain relief is a necessary part of a palliative approach?
305.13 They are mostly in pain, yes, a good example is a resident whose both legs are gone, and he's always in pain whenever we touch him, want to change him, he's always, you know, screams and says, 'just leave me', but we can't,	21. Pain is a distressing symptom for most people requiring a palliative approach?
202.41 if somebody pain they make their face and sometimes the noise, I don't know exact word 103.50 to me if they're like, ah, moaning in pain, then you're not comfortable, you don't have to be a nurse to know that. Comfort means that they're without pain, they don't—yeah it's just being without pain, I think is comfort. 202.42 Moaning, yeah. Some are still speaking but oh, 'I've got pain', you know 202.43 sometimes mentally they are okay, but other symptoms so they can go 'oh, I've got pain in my this side', so then—so there's experience, every dimension, this is one, every got different situation so somehow they can tell but sometimes they can't 202.44 What means that? (analgesia)	22. A person doesn't need to be moaning in pain to be in pain? 23. Pulling a face and making noises can indicate that a person has pain? 24. People with dementia may still be able to say that they have pain? 25. Analgesia is a the type of medication used to treat pain?
102.38.2 So even though it does take a lot of the pain—every time you move them they're still cringing or they've got a look on their face even if they can't speak. So the	26. If a person has pain it is better to leave repositioning them unless necessary?

less you have to deal with—if they've urinated or faeces or anything like that—but usually a lot of things have shut down anyway at their end stages like that so that's not necessary to touch them. I mean I've read about it and I've seen it, and it works. So that's the main thing. If it works then do it	
202.45 they report on, they tell this one, we had some are on pain chart. So we just—so they tell us this resident is on a pain chart, we just care [sic] them probably because all different situations that we know through RN handover time 203.21 we are so close with the residents with them, we actually see them, like, we are the ones who are actually giving them, like the RNs, when they fill out the pain management thing, you know, like we have to write it down, like we are the ones who are giving them all the information, cause how are their facial expressions or how they are, you know when you touch them.	27. Pain assessment tools are more accurate than simply asking the question about pain?
202.5 ..You know, different ways, they've got pain when we are moving them 202.6 You can feel it when they're making their face. So, you can [omission] body language 305.80 because you know when you're in pain, so you see them, they are in pain. They do get relief, painkillers and whatever, but…	28. Observing body language is a way of assessing pain?
101.28 he deteriorated, come back from hospital, they put him on morphine, stopped eating, dementia, stopped eating, stopped drinking, so they put him on morphine and he lasted four days 102.4 My theory on that is to make sure they are very comfortable, so, morphine starts in the lower dose, so then I up it and up it until they've probably got 15, 10 minutes	29. Giving morphine to a person with dementia hastens their death?

that they're, sort of alert out of the whole 24 hours and then right at the end stages.	
102.43 .. if you're not eating or drinking you're getting no moisture. I mean, I think that would be the worst having such a dry uncomfortable mouth; that is the worst I think. .. They can't tell us that their mouths they just want a bit of drink or something like that. Just a bit of moisture.	30. A dry mouth is one of the most common symptoms in a person who is no longer eating and drinking? 31. People who are reluctant to eat and drink are most at risk of poor oral care?
308.73 Because maybe they feel pain because they're bored, or maybe they feel pain because they're not doing anything. You know, maybe they feel pain because they want attention. So, if you give them that, then maybe, you know there's no harm in trying to talk to them	32. Pain can be physical, psychological, social and spiritual? 33. People may experience worse pain when they feel lonely?
309.38 sometimes they've got cancer it is really—even with morphine they're on morphine, they're still struggling to go. It's just the pain—you can see them, pain in the face	34. Even when a person is receiving pain relief, they can still experience pain?

Category 3: Family support	Question
101.47 when they do tell them that, they can see, yes, it is but then you go, these are the things we can put in place while this is going on and these are the people who can help you, you know, then people have got more of (pause) an open mind 301.2 some families would like to help as well 301.3 and also the family from my understanding, of what their family members going through 301.10 for families. It's very hard for them to understand what their relative is going through 301.66 I think communication with the family. I think that's one thing that I would really want to learn about, like how to understand what the family is going through and how to basically help them in what they're going through because a lot of the time I don't know what to say. I'm scared to say something and it might be wrong or it might offend them... for them to ask me and I'm able to answer it I think that's all I want to know. 308.63 if the patient, family member is dying, it's very hard for the family members to understand the situation, they're still in denial, but if you actually explain to them that everything is going to be like this	1. When families understand what is happening, they cope better? 2. Sometimes, families want and need to be able to help in the care of the person? 3. Knowing how families are coping is part of a palliative approach? 4. Communication assists in understanding what the family is going through? 5. Effective communication including body language can reflect empathy for the family's experience?
309.1.2 Sometimes the families need support too because they're grieving 309.33.2 because sometime family members even they're grieving they grieve in different ways, so they become agitated too. So they might say something, probably you don't like it but I guess we're here for the resident	6. Even before a person has died, families need support because they are grieving?
305.64 .2 dying one is that by observing them, the way they are, probably they will keep a day or maybe they ring the ambulance and they'll send to the hospital. The hospital decides whatever the problem is. They solve the problem in there and then	7. Hospital is the best place for a dying person because the problem can be identified?

sometimes they come back and sometimes they don't	
103.25 their family have a lot of say in how they want them—what comfort to them is. So for example if they don't want them to come out from their room, then we'll keep them in their room on a daily basis. Other residents we encourage them to come out. Them we don't have to because they—stay in bed, why do they have to come out for, they're in pain or they're comfortable in there and they just want to be in the quiet room or it's not as quiet in the dining room or the lounge room. They're not interested in their TV, they're on morphine, then it's much better in their rooms and just keep them comfortable, turning them, attending to their pressure area care.	8. Palliative care residents are better kept in bed where they can be repositioned and kept comfortable?
103.28 That means to me a holistic approach is not just looking at the resident, it's looking at their family and treating them—taking into consideration everyone else's thoughts not just—how to put it yeah – patient-centred care, it's not what I think. I'm just thinking, patient- centred care it's not nurse-centred care. It's what they need; I'm here for them not for myself to do help them not myself and try and make my job any quicker. We're here for them and the families and everyone that wants to be involved in their care and have a say 303.3 If there is a family member involved we are to give all the support they need from us.	9. A holistic approach is concerned with the needs of the family as well as the individual?
103.32 I never heard the term palliative care before, I just thought you died, you go to a nursing home and that's the end and you're going to die, but that's not the truth, it's their home. So now I understand there's a difference, we've got residents who are on palliative care, they also live here, but you've got the other residents which is their home, they can't go home because other people can't look after them, so we do it for them. I never understood the difference; I thought nursing home was just for really, really sick people that have no family .. I understand now even that they do have family they still can't be looked after at home but we can do better for them. We've got the equipment to look after them.	10. The home environment is where a palliative approach can be offered? 11. Residential aged care facilities are places for older people who are really sick?

308.45 I've spoken to some of the family here, some of them don't want that relative to face the reality, they're very scared of the pat[ient], oh, the mother or the father is dying, so they don't want to come, some of them is scared of caring, so it depends on how they adapt [to] that word, dying, you know that situation, end of life. Some of them is still in denial, so instead of coming in to look after the parents, they don't want to come and see that situation, so, with that certain patient, we give more attention because they need us.	12. Denial is a way that some people use to avoid the reality of a person dying?

Category 4: Social support	**Question**
301.7 Getting them out and socialising with others, especially if they're depressed or loneliness, just to get them to know other people so they're not feeling that loneliness. 301.29 Some patients are lonely, you talk to them. It's really interesting what they have to say. You never know what they're going through unless you ask I guess 309.55 they can go to depression. I think that if—just if they're lonely too. It's like some—we've got a few—one resident always keeps to himself too 302.30 .. A lot of them say they'd rather be at home with their families but then some of them they don't understand why they're here. 301.35 a lot of them don't like to interact with others so you have to respect that and get them to do something else on their own 106.9 take them out sometimes, like we don't want to keep them here like they are in jail. Sometimes, we take them on bus trips outside in the park, and they have a barbecue, whatever it is. Yes, and this is good. And, we talk with them too. We give them the life, like, you're supporting. Yeh, communication is very good here	1. Assisting a person to socialise helps with loneliness?
307.12 Emotionally—provide support emotionally, spiritually	2. Providing spiritual care involves asking a person about the things that are important to them
105.3 reassurance is a big thing, to make them feel like this is a home to them, cause a lot of them, this is their home	3. Reassurance about a person's environment is important?
307.14 So the residents don't feel that it's not their own home. Even though they are in the nursing home, they feel it's their own home. Make the environment familiar to them so that even though it's their life—end of their life, but they just like the environment there	4. In a palliative approach, providing a homely environment is important

303.8 Give them the homely environment. Get whoever family member is available to come in, have them to come in. Create an atmosphere for them so that they feel lively, rather than having a dull and boring situation in their area. So, I guess I would make it a bit fun and, you know, bright rooms, and put up the pictures	
310.11 Exercise. I think physios do a big job in this part. Exercise; activities; even simple activities—drawing or playing music or instruments 305.64 some people that you know, their sadness, it's not only because they're dying that you can see them, what internally the problem is .. I know some of the residents, that the days they are happy and the days they are sad. Especially I work in the same section for past seven years and I would know ..	5. Gentle physical stimulation and activity can improve a person's quality of life 6. Psychological wellbeing can be improved by truthful communication

Category 5: Cultural issues	**Question**
301.5. .. just to be aware of the different cultures and knowing the different cultures so that they don't do something wrong to the patient, I guess. 301. 15 .. understanding different cultures and what people, and how to approach them 301.36 Some cultures believe only a female should attend them instead of a male so you have to be aware of that so there's no problems if a male patient attends a certain resident 301.37 all cultures are different so you have to respect that. They might prefer to wear something, you know, their cultural clothing or something like that during the day and you have to be aware of that and just communicating with others so they know as well 308.67 just be there, that's how we do it. It's very annoying for the rest of the team, for example, if I'm not working in that area, all of us is there, it's very annoying for them but that's how we value our dying person, our end-of-life person	1. Taking the time to find out the cultural preferences of a person is a way of giving individualised care? 2. 'Culture' means a set of beliefs, values and practices that are learned?
308.65 here in Australia, we have different background and cultures as well, so before you attend a patient, you have to read their files, So, you know if they're Asians, Australians, whatever nationality they [are]. So, it's very easy if you know their background, it's very easy how to approach them, how to give them comfort if you know their beliefs, the value of it, how do you take care of the patient who's actually palliative.	3. If you know a person's background it is easy to provide culturally sensitive palliative care?
303.5 I guess culture shock. Because I noticed that a lot of residents are non-speaking-English background and for them to be able to understand ... it's a very difficult situation for us carers if we don't understand the language and vice versa, to the client	4. It is better to provide information about a palliative approach to people from culturally and linguistically different backgrounds in their own language?

Category 6: End of life	Question
101.50 even really demented residents have moments of clarity, you can see it, and hear it, see it and all of a sudden, they get a changed look and they'll just look at you and go, ' I want to die, just let me go', or 'why can't I do this?', they're really clear about it .. each time the person's always died within a month 101.9.3 some of them, the ones that can speak, they just say they [sic]wanna go, and they do, and you know, they have moments of clarity 102.28 That timeframe can be from one week to three weeks before they pass through the world. So it just varies. And, it varies on the way the doctors do it too with how they're sort of initiating their drugs. Whether they start off with like I said, a minimum dose and then it gets more as they're getting older—through their worst stages. 102.29 The people that have passed here have taken two, three weeks... So I think it does vary with the age 103.20 we've got some current now, but she's not going to go anywhere anytime soon, but you do know when they're actually on their deathbed	1. A person's wish to die means that a person will die soon? 2. One reason why a person may want to die is because of isolation, boredom or loneliness? 3. The early phase of dying can begin up to three weeks before a person dies? 4. Recognising when a person without cancer is dying is more difficult? 5. Signs of the dying process can be present hours to days before death occurs?
305.45 Some of them they are unconscious and some of them they still know what you do 309.39 So yeah, some of them they just go very quiet and sleep and that	6. Usually people are drowsy when they are dying?
202.39 we report to a RN, because if something is different, anything is abnormal, any signs or sometimes they are all right morning but sometimes—suddenly their head is like that and then we just go to sister, what's going on, this and that then they see oh yes. Even sometimes in the chair when we take them, so people, things happening 202.40 Suddenly she just—minute she got heart attack we just—she just passed away in that chair. Yeah, so sometimes things quickly, but sometimes we just slowly	7. For some people death may occur more quickly than expected, while for others the dying process may be longer than expected?

things happening 301.20 Some people we don't really expect it and they just go quickly. Then sometimes the ones that are in palliative care, it takes a longer time for them to go as well 301.42 A lot of patients we had here they go within a week once they're in palliative care. They come and that's it. Once we had one that was for two months but then the least time we had was a week	
102.30 I know if I've nursed them for a long time. They stop eating, drinking. They're quite lethargic, they just sort of want to be left alone. They don't like you man-handling them a lot either. 202.33 Not eating, not drinking, everything is coming out. We put sometimes ice because their lips are very dry, we put some ice just lips dry, you can see it. This is if they can't swallow, they can't take anything inside. I know some people's heart, they take longer days; some are only two or three days, some are two weeks. Everybody's a different situation but when they give up the eating and drinking this means…	8. A lack of interest in food and fluids and wanting to be left alone can signal the early phase of dying?
103.22 , if I'm dealing with them yeah, they go through the change, the breathing change	9. A change in breathing indicates that a person is actively dying?
309.68 You just—I think you just know they are going. You know them, the way they change—how they change so quick ... I think that breathing, I don't like hearing the breathing of the residents	10. Changes in breathing are of normal part of the dying process?
202.34 Some are [?gurgling] [unclear] coming out so then we don't stop it, or then we ask RN, oh sorry, this male or female person, we can't do any so then they stop it, just handle them gently in bed and side to side, that's the palliative situation	11. Gentle repositioning can help people with respiratory secretions who are approaching death?
202.38 Some, they may—like their feet and [unclear] and went to blue, colour changing and very yellow colour or eyes are just different. You can judge—you just can observe it, this is something wrong, so we can't do this person to be move. So	12. Blue colouration (cyanosis) to the body's legs, feet and hands is a sign of the body's circulation shutting down and of death?

then we on duty our RN, we can tell them what the situation happened, what we will do. So their decision we will follow	
202.57 What bereavement? 202.63 sometimes you just come to work and suddenly see oh, that gent's (sic) passed away and you're just in really shock and just something, just burst in tears or whatever. He was all right, he was all right, what happened, because attachment 202.75 Like palliative care situations, we can't do anything else. If they are really […?] bad situations we just—it's the only comfort we can do. What can we care them nicely and comfort them and comfort the family, support family, the situation they are going on. So that's all I can say	13. Bereavement is the reaction to loss and also includes the process of healing from the loss? 14. To be 'doing everything' to improve a dying person's comfort including spending time with the person helps family members cope with the dying process?
307.20 It's the last stage. If something happens, then to deal with the family, to support them. I know grief and loss [echoes]. It's really hard to, but we have to go through that	15. Grief and loss is the last stage after a person has died?

Category 7: Team approach	**Question**
101.6 it's a team environment 103.17 I think the team and the environment you're in counts for a lot of that, you know, if you don't have team work, you can't work together, you know, you can't help each other, so you need a lot of team work. And, you need to be able to communicate with people more efficiently ... I think it's the team that you work with, that you need to be able to express more, find out more, or learn more, you know 301.16 older nurses that have been here longer than me. They teach me things how to, especially for patients that I don't know. They teach me how their routine and getting to know them 301.5.2 our job we don't really know what's going on, sometimes it's very hard for us because we don't—we're not very professional like—not professional what's the word—well for myself I don't really know everything. So, for me to have someone else explain it more is better than me	1. A team approach improves care to the person needing palliative care? 2. Senior staff who have been working longer know the best care routines? 3. Effective communication and teamwork are essential factors in a palliative approach?
307.3 It's us—the nurses, the carers—who advise in work, like the doctors, the specialist, Allied Health carers—all those 303.12 the correct procedures of lifting her and turning her and whatnot wasn't there because no one in our family had that knowledge	4. Both primary carers and specialists professionals work together in a palliative approach?
202.9 the DON, the deputy DON, the RN, they will tell us what to do when in this situation, they will tell us nurses what we will do. Those residents who are in palliative care	5. It is up to management and registered nurses to identify those people who require a palliative approach?
203.2 .. that's coming from our management or RNs or something, you know, like and they are the ones telling us and even though, when we are attending the patients, we actually understand too how the situation's going down.. we are the	6. All care providers are involved in a palliative approach?

ones, actually, the nurses and we give them our feedback to them .. we are all surrounding and we are all involved	
308.63.2 I've seen them do resident care meetings for palliative people, so they're going to orient the family what's going to happen: if they do this, what's going to happen to them, if they don't what's going to happen to them as well .. they have to tell the family what's going to happen to that patient if they don't do it or if they do something to a patient, so they already briefing the family	7. A family conference helps to inform the family what is going on with the person and what the options for care are?
308.14 There is a team who actually talk to the family. What do they want to improve more? Or do they have any concern to the resident? So we actually discuss that 205.2 All staff is involved in the palliative care. One person can't do anything 309.3 The nurses, the doctors, RNs, the nurses, all of them, the physio's and the speech paths. All the health care gets involved for everything for them to [look them] diet, to [look them] exercises, the pain relief for them so they don't suffer, everyone 309.44 Well first of all the nurses are there to make them comfortable. The doctors are there to relieve them pain everything. The speech path see if they can actually eat anything or—and drink anything. So basically every person that is involved in palliative care, it's a really, really big deal. We can't—they can't do without nurses. Definitely without doctors they are nothing, without RNs, nothing. So if none of us get involved then what's going to happen to the resident? 309.45 We need a team work together to make someone comfortable. So let them go in peace	8. A team approach can improve the quality of a person's care? 9. It takes a team approach to offer palliative care? 10. A multidisciplinary team approach provides expertise in different aspects of a person's care?
310.37 Each day, you don't know what you're going to go against. But, even for the hardest part in this facility, it'll be working, you need team work, you need team work and you need help, cause it's not an easy job. So, hard parts can, would be difficult residents, days where there's not enough help and then you'll just get	11. The multidisciplinary team approach is an important part of a palliative approach because the different forms of distress experienced by people and their families requires a broad range

drained emotionally and physically	of skills?
309.45 We need a team work together to make someone comfortable. So let them go in peace	12. It takes a team approach to keep a person comfortable?

Category 8: Professional development	**Question**
302.20 , more education, if education comes more, then nurses will be aware like what to do, what not to do, because at times, sometimes we forget, you know like, yeh. If it's like more educations are coming every now and then, we'll be knowing, it's sort of like a refreshing course. It will be helpful 102.16 I think it's just how I approach things and learn. I read a lot about different types of dementia, there's lots of different types, and at the moment, I'm reading about the drug and alcohol dementias, and what part of the brain and things like that, so, and, I do ask questions, I ask a lot of questions 103.4 I think we need more training, you know, when I came here, whatever you've got, I had my cert. III, that's all, you know. I think we need more education .. I think there's always more to be learnt about it, you know what I mean and how to treat each one as an individual .. you just need to learn more, and more about the diseases and why they're like that 306.9 knowledge about some disease and how to manage these people, like what they needs and do .. bed sore, how to cope with these problems and keep clean, keep clean the mouth and every part of the body	1. Professional development is about learning and asking questions? 2. Knowledge based on evidence is better than knowledge based on practice? 3. Knowing what to do is not the same as evidence-based knowledge?
105.6.3 We need to have a little bit more preparation beforehand instead of learning it as we go. Because sometimes, palliative care, they're here for a long time, other times they're only here for a couple of days. So, if you know a bit more, that gives you that time before instead of after 203.11 we understand a lot of things when we do over and over the things, you know, like, that's why I think we need a lot of education as well 309.62 Sometimes you just feel like automatically you know exactly what to do. Even though you might not have a training with it, it just comes	4. Carers don't need professional development if they are able to learn on the job?
So we need more in grieving, more education in grieving…	5. How we understand grieving is based on evidence?

Skills Categories

Category 1: Observing and documenting	Statement
307.36 skills is .. follow whatever is in the care plans according to their illness or disease, whatever they are going through, and provide support according to that. 304.22 to read what's going on with them and that. One of the good skills is to acknowledge what you're doing and to make sure that you're doing it properly. If you don't read the information that you get on the resident, patient and the palliative care system and that, and listening to the RN, the registered nurses, the doctors and all that. They're skills that I've learned that if I'm able to do all that stuff, I'm able to give that resident, patient, the care that they really need 307.9.2 Read—what you call it—upgrade the care plans according to their illness	1. I provide care according to an individual's care plan 2. I read clinical information in individual progress notes 3. I update individual care plans based on observation of the individual
306.1 do our best to keep them clean and understand what they need in this time, and observe them, and report to our supervisor 306.6 just understand the needs of the resident, what they need at this stage, like keep them clean and secure, like a gentle approach .. observe them and report to supervisor.	4. I report an individual's need to the person in charge 5. I provide individualised personal care
201.25 If someone can't help themself cut food, you help them, you feed them, you look after their daily needs, you groom them, you shower them, you shave them and be really—you have to be -understand what they want from you and what they can do and what they can't do 301.38 A lot of things we find out during—when we're doing our rounds in the morning or in the afternoon. Things that we didn't even know they can do or they don't want to do. What time they prefer to have a shower or things like that. So we find out just doing our rounds	6. I observe what an individual can do independently 7. I observe what an individual's needs are

306.12 I became more patient and I gain more skills how to cope with people and I gain skills how to observe people, their, like changes, like more observant with people, their behaviour, their appearance, skin, like ill condition or some changes	8. I provide individualised personal care
308.14.2 We have to reassess them every now and then if there's any changes so we know what to give to them 308.36 We actually assess the patient every day here 308.37 We check the resident if they're declining or if there any—improvement to the patient, even a little bit. ..- as assistant in nursing—because we actually assist them every day ... We know if the residents change a little bit in decrease or increase of any health condition. So we assess them. If there's any changes, we tell the sister	9. I monitor and report any changes in an individual's condition.
308.24 I have to prioritise. It's not because I have favourites. It's just I have to prioritise the needs of the patient	10. I prioritise the needs of individuals
307.18 when we know their illness, we can do the advanced care directives. We know what they want, what they are expecting when it's their end of life so that we can follow and provide support for them	11. I provide care in line with advanced care directives.

Category 2: Providing physical comfort	**Statement**
201.26 As long as person can't feed themselves but they can still eat, whoever is looking after them you try your best to feed them, however much they can eat. If someone doesn't eat at all, they've given up, so you talk to their family and explain what's their condition and sometimes families put them on a peg tube while others just want them to go and be—and they agree with the decision, what they've made 301.33 If they can still feed themselves we encourage them because once you lose that you can't and it's good for their body movement as well to keep moving still. Little things that they can do like comb their hair or something like that, we still let them do that to let them still think they can do things on their own without us taking over everything 206.7 ... feed them proper[ly] so they don't face that difficulty, if they have a difficulty of swallow[ing]. So we should wait before we give the spoon, they should swallow properly, before we give the next food	1. I observe an individual's ability to feed themselves 2. I safely feed an individual
206.8 and, secondly, any bed sore we should clean them properly and make sure that infection control never goes from one resident to another resident without the gloves or without	3. I practice infection control
301.23 ... giving them fluids, offering them anything that they need just to be happy on that last stage.	4. I encourage fluids on a regular basis
202.7 ..if they're not eating solid food, we have to give them drink, to keep mouth, you know. Some residents mouth[s] is very dry. When they are palliative, we give ice, something, dehydrate more. That sort of thing, and icecream, sometimes, we give them a little bit to keep a little bit swallow[ing].	5. I provide mouth care based on my observation of individual need
304.8.2 they're repositioned, their skin integrity is looked after properly, and, as I said, make sure they're comfortable at all times	6. I observe for problems with an individual's skin

	7. I provide comfort that a person needs
305.45 what we do make them comfortable is reposition them every two hours, we do normally, and bed-bath them. Not to take them out of the bed, but we sponge them and groom them in bed 303.18 I have learned the easier and a quicker way in doing that. So I don't take a lot of time or put them in a lot of distress when I'm turning or positioning them 304.5 Try to make them comfortable, repositioning them. Make sure that they're looked after. They're in the right state where they are comfortable and well looked after	8. I position people for comfort

Category 3: Managing pain and symptoms	Statement
202.41 … when we—if somebody[sic] pain they make their face and sometimes the noise, I don't know exact word … Some are still speaking but oh, I've got pain, you know. 102.49 Well you know when they're in pain. Even if they can't tell you, you know. You know these people upside down sort of thing. That's all how I can explain it. I just know. I just think that's when it's up to is AINs to enforce it with the RNs—just to let them know that this man, and just keep going; no he's not doing this, he's not doing this, he's not doing that sort of thing so we need some pain relief for him. So that's how I think it starts. I know this person. I know he's in pain. This isn't him, so please, inform the RN, we need some pain relief	1. I observe for pain when I provide care 2. I ask an individual whether she/he has pain 3. I report pain to the RN or person in charge
202.45 .. Yeah, they report on, they tell this one, we had some are on pain chart. So we just—so they tell us this resident is on a pain chart, we just care them probably because all different situations that we know through RN handover time	4. I record pain using a pain assessment tool in line with care directives
302.5 we need to put them in a comfort position so that they are more relaxed, not in pain. 309.87 just make them comfortable. Make them really comfortable. I can't take the pain away but I can reposition them so they don't be sore and just make them comfortable as much as I can for them	5. I manage an individual's pain by using non-medication strategies, such as repositioning or gentle massage 6. I evaluate the effectiveness of pain management strategies
102.31 We see how many times he opens his bowels, how he urinates, he's got a catheter anyway so we can see how much of the output; so he's still drinking but he's not eating. He's on thickened fluids too so he's actually still holding a lot of that down. 308.76 if the patient is behaving very well and there's a sudden change the following day, I'd tell the RN. The RN would tell me can you please check the urine, you do a UA, or can you please check the bowel chart, maybe she's constipated, you know those things. So, we do that, we actually communicate, so after that they will call a doctor or they will do something or they will assess something or they will give medication just	7. I monitor and report bladder or bowel problems

to get rid of that constipation	
202.34 Some are [gurgling] [sic] coming out so then we don't stop it, or then we ask RN … we can't do any so then they stop it, just handle them gently in bed and side to side, that's the palliative situation	8. I monitor and report problems with noisy breathing
308.75 I know my residents very well… so if there's any changes, you know straight away, if the patient's hallucinating or if the patient's, there's behaviour change, we know straight away that there's something wrong with them. And maybe they have UTI, constipated, you know, you tell it to the RN straight away .. you report it straight away so they can take some action	9. I monitor and report increasing confusion

Category 4: Supporting Families	Statement
301.25 We talk to a lot of families about anything and we listen. Most of the time all we do is listen. We don't want to say something to—that is wrong so all we do is listen and a lot of them appreciate just listening 301.68 Listening. I think listening, interacting with the families and with the patient as well. 301.17 Customer service is one big thing cause you have to deal with a lot of people day in and day out 304.18 The care that I give to people; they're comfortable; the conversations that I have with them to find out, and especially with the family members, to find out about them and everything 304.19 Being able to talk to people 304.19.2 able to relate to the family member side of things plus the staff member side of things 301.38.2 . If they can't communicate with us because of language barrier we usually ask the family. When does your mother prefer to have a shower; what does she prefer to drink or eat because we've seen she doesn't want to eat this. So we communicate a lot with the families 301.24 Basically just letting them know it's part of life what their family member's going through. Also we offer education to them if they require it, just to give pamphlets about it or talk to them more on how—what their family member is going through .... so it's basically just supporting them 103.40 we do, because they will ask the RN, but they do understand that we're the ones more closer with them, sometimes they do. They	1. I support families by addressing their concerns 2. I communicate with families by providing information

will come and talk to us and we'll try and explain as much as we can	
102.50 We have to inform the families. Look it's all well and good to be all there, talk laugh. Because I still reckon that they can hear you. But don't feed them. And I know they can see their family's dry lips—it's all cracked, and the tongue's starting to hang out a little bit and things like that. I know they want to feed them. I know they want to give them something to eat, drink. But you've just to be really stern and say, please don't do it. It's for their own benefits. We're not being cruel and mean. We're doing it for them so they don't have to suffer any more. So that's how I always explain it to the families.	3. I know how to talk to families when their relative is dying
201.28 we explain what their condition is. Like say if someone—if I've been looking after someone for quite a while, they've been eating alright and over the period of time they've gone down and they don't eat anymore, they no longer want to—or if they want your help so you give your feedback. They talk to the resident's family and they make the decision 301.10 .. so it's our job to try to get them to understand it, cause sometimes they get angry 301.2 we help the family as well to understand what it is and if they, cause some families would like to help as well, so we teach them the right things to do in palliative care 301.53 A lot of our families they ask us: we don't really understand this, what can we do. A lot of times we provide education for them. We tell them: go on this website you'll find all this information, or do you want us to refer you to someone to help you. 301.53.4 just to get that family more information and someone else who—that knows more than us, we provide that	4. I explain to families about the condition of their relative

102.8.2 you really need to reassure them, and hold their hands, and make them feel like there a part of this too, this journey cause it's a journey for them too as it is for the resident, that's passing. 202.60 when somebody pass, the family come, we just [.. unclear..]them, we just sit them, with family, asking them a cup of tea and hug them, [so they're] sorry 309.33 communication skills is the best because you will be able—you're going to communicate a lot especially when you see a family member is grieving and everything and they constantly are with you asking you questions	5. I support families when they are grieving

Category 5: Adopting a Team Approach	**Statement**
1101.34.2 we went over his head, then we went over someone else's head and went straight to the DON. Ten minutes later, the DON come down … and ten minutes later, the doctor's here, coz, if we get on the phone, and ten minutes later the doctor's here 101.7.3 our educator said, 'Jump on them, if they're not listening, jump on them' 101.32.2 if you don't think they're doing their jobs, jump on them, abuse them, have a go at them, and if they won't, come and see us, so that's what we do.	1. I report the needs of individuals to the registered nurse or person in charge
101.33 they need a voice and because they can't speak, a lot of them can't speak, or don't want to speak, a lot of them can speak but just choose not to, depends who they speak to, they need a voice 101.2 I pretty much begged the doctor to give her morphine, take her off the peg; 103.37.2 I think that's wrong too, you're not even here to see her, the way that she's deteriorated and—it must be painful, whatever death they're dying from. I don't like it, I don't agree with it, that's why I'm trying to—I'm doing something else, not just be a nursing assistant I want to move up. I think we're advocates for them, but I don't think sometimes that works 301.31 It's very good to communicate with your residents because if there's any changes, it's better to come from them than to not know at all.	2. I raise the concerns of (advocate for) the people in my care
301.27 we refer them to a specialist or to a doctor that knows better and they can provide better information for them that what we can.	3. I communicate with doctors about the individuals in my care, as necessary

Sometimes we also ask our boss—we tell our boss what's going on 301.26 we refer them to more professional people than us that know better than what we know, like about certain things that their mother or father is going through.	4. I direct families to other members of the care team when they need further advice 5. I communicate with other allied health providers about the needs of an individual
101.7.2 We've got to be able to speak our opinions and we've got to be heard. Yes, we're only AINs, but we're the ones who deal with them day to day	6. I contribute at team meetings or family conferences 7. I contribute to problem-solving to seek solutions 8. I support team members

Category 6: Providing End-of-life care	Statement
101.28 I just closed his eyelids and he took his last breath but he went quietly, pain free and with dignity. 102.5.2 we just put him in one of the rooms by himself, because, he's Lebanese, there's lots and lots of family, so you have to be prepared to talk to the families as well as see what you're doing 202.66 first time you feel scared, you don't want to see, but I don't know, now is okay. Some are still—some staff, they don't want, they can't handle .. death, after death 308.57 there's not actually any education for that, briefly. But because I'm an assistant in nursing what we do is if they're actually going, we just clean them and everything, that's how we do it. RNs have different jobs to do as well, so that's our thing. So, if something happens to them, we just clean them and put them in there	1. I maintain the dignity of a dying individual 2. I provide comfort and privacy for a dying person and his/her family 3. I am attentive to the care of a dying person 4. I provide post-mortem care
202.33 Not eating, not drinking, everything is coming out. We put sometimes ice because their lips are very dry, we put some ice just lips dry, you can see it. This is if they can't swallow, they can't take anything inside. I know some people's heart, they take longer days; some are only two or three days, some are two weeks. Everybody's a different situation but when they give up the eating and drinking this means… 202.38 Some, they may—like their feet and [unclear] and went to blue, colour changing and very yellow colour or eyes are just different. You can judge- you just can observe it, this is something wrong, so we can't do this person to be move. So then we on duty our RN, we can tell them what the situation happened, what we will do. So their decision we will	5. I recognise the signs when an individual is approaching the end of life

follow.	
307.22 I have confidence if I have to face this with my own family .. even if I see grief or loss or something like that, I always stay back. I know I become emotional very quickly, but now—this time I'm more confident to handle that	6. I manage my own emotional responses when a person I have been caring for has died.

Category 7:Providing Social Care	**Statement**
301.34 we try to put that into their routine through the day, to comb their hair or feed (themselves) but we still supervise and assist if they require it, but if not, then it's very good for them to be still doing that for themselves. .. Try to get the residents to keep their independence; if they're able to walk, try to get them to get up and go to the toilet; have them on the toilet in schedule where, if they're on that schedule that they know, instead of having to put them on incontinence aids and that, where they can actually get up and go to the toilet. Prompt them to feed themselves if they're able to... if they're able to move their body parts and all that, try to get them to do some of the showering themselves even if it's just washing the face, or that, get them to do something for themselves. 304.11.2 make sure that they're able to get up and walk to the toilet, even if we've got to use a lifter and all that, to get them where they know, OK, we can put them on to the toilet, to say, OK, use the toilet. 304.14 to get residents to keep their quality of life, to get them to move around, to try and feed themselves	1. I encourage independence
102.7.2 so making them, just feeling relaxed with you, so it's just the way you approach them, I think. 102.24 I mean I notice the ones that have been here for years, they look at us if we have a lot of other people coming in or younger girls coming in, they seem to just put their eyes on us. As if to say…. I know you. So even if they can't speak, they've just got that look. So they just need the older ones I think with more experience 103.30 I went to feed her, she wouldn't eat, she was very slow to open her mouth. I went, I'm not going to force her but I went to ask somebody else, she's not eating, it is me, can you try and feed her? She ate for them .. I'm just trying to make my presence more with her because she doesn't know me obviously because she's not—she can't see but she hears, so she's solely basing me on my voice, she hasn't	2. I promote confidence 3. I provide reassurance

heard from me much. So that's what I mean, encouraged by other people 105.1 So, making them comfortable, less worry, no stress, talk to them as much as possible, just reassurance and comfort 203.9 ..the main experience is you have to understand the residents and how to talk to them ... when we see their behaviour like we try to do another way and to settle them 301.30 We try to explain to them why like, you know, maybe they're busy working, no one's at home to look after them so it's better to be here, to be safe, than being at home and something happens and no one's there 202.25 more relaxed because she believe me; what I'm saying to her she will do. This morning she just asking—I didn't ask her but she said oh, you are very good, I love you, I like you. Oh, thank you very much, this sort of comment when we listen 201.40 You spend time with everyone but it depends upon the person. There are some people who would like to talk to you but there are others, they don't want to socialise. They keep to themself and with particular patients, residents, when you spend time with them they feel that they've been looked after and they feel happy about it 204.15 while feeding them, some other activity like just for fun. Sitting with them and playing games, reading newspaper and talk to them one on one. 202.12 we will deal with them nicely and, what situations happens we will deal with, we will work it out. If somebody behaving aggressive, we leave him or her for a while. We know what the situation is. We will handle it	
301.37 we have to look into that and then we write it down: do not send a (sic) female. We have to respect what they want, be aware of what they want to do 302.9 we give them better care. We provide them with what they want.	4. I respect individual preferences

303.6 be calm, be patient and understand what they are going through. That's the main thing I have noticed. You have to be very, very calm 203.17 my patience and (pause) patience and sometimes, eh, understanding them 306.10 be patient with people because sometimes people not do it like you want to, like some don't listen to you or don't argue with you and, like, resist you, your actions … my caring skills I think, yeh, cause I do care	5. I demonstrate calmness, patience and understanding in the care I provide
301.31 just talk to your residents and find out what they're not happy with or what they're happy with and, you know, that we can provide better care for them because a lot of time you don't know what they want. So to talk to them and find out you're like, we can change your care plan to this and that to suit their needs 201.40 You spend time with everyone but it depends upon the person. There are some people who would like to talk to you but there are others, they don't want to socialise. They keep to themselves and with particular patients, residents, when you spend time with them they feel that they've been looked after and they feel happy about it 204.15 while feeding them, some other activity like just for fun. Sitting with them and playing games, reading newspaper and talk to them one on one. 301.35 we can ask them. You ask them if they want to eat certain food or what they would like to—prefer to drink or something like that. 301.35.2 never force them to do what they don't want to do. It's not a good thing to say: go and play bingo, if they're not—maybe they've never done that, so yeah just asking them. 308.29.2 Talking to them, actually learning from what they experience because you see them helpless but you don't do anything. Just keep writing, but if you actually	6. I build a relationship with the people I care for

talk to them you will gain more 301.22 making them comfortable and be there just to see how they are, comfort them. You know just let them know that there's someone there that cares.	
201.40 You provide them support that there is someone who is actually willing to listen to you, what they have to say 202.25 more relaxed because she believe me; what I'm saying to her she will do. This morning she just asking—I didn't ask her but she said oh, you are very good, I love you, I like you. Oh, thank you very much, this sort of comment when we listen 301.25 We talk to a lot of families about anything and we listen. Most of the time all we do is listen. We don't want to say something to—that is wrong so all we do is listen and a lot of them appreciate just listening 301.68 Listening. I think listening, interacting with the families and with the patient as well. 309.56 Listening to them. The first thing is just listening to them .. Always be there for them. One day they're going to crack and open to you—and listen 309.60 Listening to them—just listening to them. That's about it. If you—we do have a lot of residents that are very good even they can't walk and that. Sometime even if we have two minutes we just go and sit there and listen—they've got a lot to say	7. I actively listen to the people I care for
301.46.2 I think just make them happy because a lot of them come in here and they think that's it, there's nothing else they can do for themselves. So having that just brings happiness to them I guess. They feel more at home. 105.3.2 Try and make a bond with them cause a lot of cases we're their family. So, reassurance, security, you know, don't let them feel like they're here for fear, no fear to them, yeh, make them feel relaxed, this is the next stage of their life. It's not as bad as they think, a lot of them. Make them feel as much as their home as	8. I create a homelike environment 9. I support an individual to feel at home 10. I maintain an individual's safety

possible	
202.12 we will deal with them nicely and, what situations happens we will deal with, we will work it out. If somebody behaving aggressive, we leave him or her for a while. We know what the situation is. We will handle it 305.67 some [aggressive] residents and it depends on their mood, especially at this time. Sundowning changes their mood. When they are aggressive and we do leave them, even some palliative patients they are somehow—I won't say alert, but they know what you do. Some of them, they are unconscious. But if they are not—I mean, they don't want us to touch them. They scream. We leave them, but it's not that we leave-leave them. We do come back, probably see that the patient has settled down. We do go back and do that. But we just don't want to make them—they are aggressive—make them more aggressive 310.20 If they're being too resistant, like too aggressive or naughty, just walk away and come back to them later. At the beginning I wouldn't have done that. I would have kept going and thinking why isn't this resident like complying with me? Then I think as you go you learn these things 310.43 If you're asking a resident to have a shower and they keep refusing we can't force them, so we have to leave them. But what if they haven't had a shower in two weeks and they keep refusing? You're going to have to push it just a little bit but to an extent. So a new way to approach them, not trick them either is just say, 'let's go for a walk' and get them closer to the bathroom, and once we're outside the door, 'oh, do you want to go to the toilet' and from there, it'll lead to the other and then she'll have a shower 301.50 sometimes you just have to not get angry at them and realise that's part of life isn't it.	11. I am able to care for a person with difficult behaviours
101.15.2 but different techniques in managing those people, in conflict resolution	12. I resolve conflict

Category 8: Professional development and Reflection	Statement
309.19 When you work in a nursing home you appreciate your life, you look after your life differently to before, you never think about anything can happen. Now you think you better enjoy that time that you have left before something happens 309.89 .. You go in someone's room and you see the pictures on the wall and then from the baby there—what as they were growing and then you look at them the way they are, come on, tell me that's not hurtful. You don't think that in 20 years or 30 years or maybe five years you're going to be in there 310.13 if I were stuck in a nursing home, I'd get confused—if I had dementia I'd get confused waking up and seeing where am I, like who are all these strangers? And if you go out on a bus trip you see something that you recognize—you see the world; like you see the streets, the houses, the green, the grass, everything. So I think that's very good for them 310.16 coming into a nursing home you realise so many things about life and aged care and old people. When you're younger you don't have knowledge about them. You'd think that they're normal, they're going to grow up at home, whatever, but when you come in here you see what they deal with when you're ageing. They go through so many things; sometimes they don't even remember their family. Like it's hard. I think it's a struggle. I don't like age 310.38 You look at life differently. Because before coming into this place, this job, I didn't care of life enough. Then when you come here, you see these people who have gone through ninety years or so many	1. I reflect on my performance and attitudes when providing a palliative approach

experiences. It makes you appreciate things and appreciate life 310.27 adapting to each and every different resident; how they act towards you	
105.24 the first time I've ever come across a thrache[ostomy]. I had no idea, no idea what to do, so I was lucky that my partner had more experience and could show me, pass that knowledge on to me, but still, I would be, [sic] cause it was only for a short time, if that situation came up again I wouldn't be confident enough to pass that on, I haven t had enough, yeh. I'd have to rely on more training or somebody with that knowledge to be with me	2. When I am unsure how to do something, I seek advice
102.18 Your approachability, just the way you approach people, it's just your main thing all round. It's the way you approach your residents and their relatives, so, uhm, you've got to be able to have those people skills and that is what you learn as you get older: the people skills ... .I think it comes with experience and practice	3. I find ways to manage stressful situations with individuals and families
202.21.2 Skill is like, manually handling, lifter this kind of thing you are doing. That is a skill. We didn't use that, this kind of device before. So, every time, this new device comes, it's new. So this means day by day, we just learning more. So build the skill better. We don't be hesitate, oh, god, how can I do my trolley bath, so this is every day practice, confidence more, so better skill and handling 205.22 Everything is new to me, even the way we're making beds, the way we're changing people, the way we're manual handling, everything is brand new to me, so it's all new skills.	4. I practice manual handling

Attitude Categories

Category 1: A palliative approach	**Statement**
101.2 The ones who have no quality of life; the fact that they're stuck in a bed, or stuck in a chair, they can't speak, they're on a peg feed, it's not good	1. A palliative approach can help improve a person's quality of life.
305.79 we have tried everything with the patient. That's not working and you know that it's not working. I would say it's suffering, because you do your best, you want to give that care and you've done—you tried your best. You did everything and it's not working 311.30 I don't know what can I do with the residents. That's what I say. It's up to the God, you know?	2. I am unable to improve a person's quality of life with a palliative approach.
101.63. when residents become palliative, there has to be cut and dried lines, you can't blur them .. from a family point of view, they need to understand that once that person's palliative, there's only certain things we're allowed to do .. a lot of people they come to us, they get diarrhoea, they get the flu, they get crook, they stop drinking, they get dehydrated, then we send them off. It's a lot of money but .. once a person becomes palliative it should be what it says, palliative, not off to hospital, not back to here 103.48 because a lot of people think what, coming to die what do you mean? Shouldn't they be in a hospital? No. In a hospital you're just a number, here you're not, you're a person 305.33.2 if it was my father-in-law, he's 86, I don't want him to die, it's better to send to the hospital than you know, him suffering .. in the hospital, there's different types of medications that .. relieves you of your pain .. nursing homes should have the equipment the hospitals have 305.41.2 I would send them to the hospital, as much as the treatment goes on	3. Hospital is the best place for a dying person because their problems can be identified and treated.

305.65.2 doesn't matter is my family or person that I know, that I look after every day. They will help them to go to the hospital and because of we don't have much equipment here in the nursing home, there's more in the hospital. So I would prefer them to go to the hospital. Send them to the hospital	
102.21 Palliative care's just quite hard to deal with anyway, at any stages for us, the families and the residents. .. I reckon that palliative care is probably a good advantage for them. 302.13 Looking after someone that's on a palliative care regime is hard, cause you've got to constantly make sure that they're comfortable 102.22 it's quite difficult with the families, and it's just how you approach it. Like I said, I'm older I know how to approach people a lot better because I've been doing it a long time. 101.21.2 It's very hard and, sometimes, you get attached, so there's a moral conflict and what's in the back of my mind, so how do we juggle it. As AINs it's hard, tell the family, keep your mouth shut, for God's just let them go 108.12 The emotional part. I thinks it's very hard 302.11 When family visits and when they can't see their loved ones in that condition, that's the hardest part, I find it. . when the family visits and sees the loved ones in that condition, in the bed, or in the chair 303.18 When I first started I was a bit scared to lift them and turn them. 107.11 I find the hardest part is when they have their behaviour problems and they can be quite abusive towards you. I find that's quite hard to sort of take, but that comes with their behaviour	4. I find it hard to provide care with a palliative approach (revised to: I find it difficult to care for people who are suffering.)
201.7 Spend more time with them one on one. That's the most important thing I think, cause the rest everything we do care for them. We do attend their personal	5. Spending time with a person who is approaching the end of life is important.

care but one on one is the main thing 308.68 .. if I have time what am I going to as well, I'd just sit there and talk to them, it's easy you know to hear me that someone is there for that person, even though the family's not there there's still someone there for him, or that patient, so I think that's the most important thing for them at that certain moment	
301.12 .. just to care for someone who can't do things on their own is a big, that's the biggest reward for me, 301.14 .. just to care for someone else that can't care for themselves. 301.60 I love my job and I don't know what I will do without this job. I don't know, I just love looking after them I guess. 302.13 I love this, just to give cares cause it's good, I think this is the best place to work. Yeh, it's the best place to work because you can just help others, the elderly people, especially here 302.16.2 .. at the end I just feel like OK, I helped them cause I always just think that I'm helping them. So, at the end of the shift, I feel like I did something for them which they can't do it themselves. That's why I'm here to help them. 305. 26 end of the day, I feel I've done my best .. the love I've given them, the care I've given them .. I feel I'm proud of myself that, you know, the end of the day, I've done whatever I could 307.25 whatever I thought—as through I went, I found it in the residents. I made a good relationship ..—even with the staff and with the residents too. As ..I worked, I found it more and more—the relationship with the residents 310.17 I came here not knowing that I was going to love my job, and now I love it because I know that they need help and not everyone can do it. I mean it is a hard job	6. Caring for a person with a palliative approach is rewarding.
301.6 .. what you're supposed to do in palliative care cause it's not the same as	7. Providing a palliative approach is not the

normal nursing. 301.39.2 Normal nursing's everyday routine that we go through with the residents. I think palliative is more difficult than normal nursing. Normal nursing's just providing just normal care, everyday care, for them. Palliative care is like we have to be there more for that person and just providing more care for them because everything you'll be doing yourself, not the person because they can't do it on their own 307.21 they are the elders, similar to my parents and to my great—grandparents, great-grandparents—that's what I think. I have something inside that makes me feel always when I attend a resident, either it's in palliative care or normal. It feels as if it's my own parents. That's what I think. 103.19 Ah well, well they're not going to go home are they, that's what I meant by, they're here to die basically, come in to die	same as usual care.
101.18 sometimes the guidelines contradict with your moral (pause) what you think to be true .. 101.22.2 With Huntington's, why put them on a PEG feed? With Parkinson's, why put them on a PEG feed? Why? They're prolonging a person's life, for what. Again, I would not end up in that situation and, if i did, and, if, they say, before you become completely gone, there are moments of clarity 101.23 just to be thrown in a chair and left in a chair all day, to be thrown around in bed, you can't speak, you can't do nothing, that's no life. 101.24 if there's a chance of recovery, I'm all for that. But, if three doctors say this person's not going to get better, why can't I. 101.25 like Huntington's or Parkinson's why put them on a PEG feed, it should be illegal. You wouldn't do that to a pet dog, why do that to a person I'm dead against peg feeds	8. Seeing people who are never going to get better being fed through a PEG feeding tube distresses me.

103.31 She is on palliative care but I'm not going to starve her, but I know she does eat, so the family comes and feeds her. Just because she's on palliative doesn't mean that I'm not going to feed her, there's other ways that you've got to go around it 103.6 I think you've got to encourage feeding even if they don't want to eat, you need to encourage the feeding, even if it takes longer, don't give up, just keep trying, you know what I mean, cause if they don't eat, don't drink, they're going to die… I think you should keep encouraging, keep trying, if you can't do it, get somebody else to try, you know what I mean, maybe it's you that they don't want to relate to or something like that, you know, somebody else can take over if you're stressed about it, if it's irritating you, you just walk away from it, get somebody else to help you 311.21 when I go for the feeding time, when I go and make them—like you have a nice food, and you have to eat it. Imagine that you are at home and your daughter or son is giving you the food. Just make them—it's your home here, you know? Just to make—encourage them. Then I let them—yeah, you have to eat so that we can—after dinner then we can go for late night shopping, all this.	9. I always encourage palliative care residents to eat even if they lack interest.
106.7 give them high care, give them as much as I can, you know what I mean, as much as I can. Uhm, write everything about the changes in the skin, wash them, we shower them, change them, we do as much as we can for those people because they need a lot 301.1 to look after that person to the best that we can, basically doing everything for them cause they require it more than others, basically cause they can't do it for themselves. 309.1 they're the people that actually need your care more than anyone, and especially the ones that can't actually do anything for themselves, so needs a lot of caring and support too 309.90 You've got a bed bound resident in palliative care they need more attention	10. Providing a palliative approach based on an individual's wishes improves their quality of life.

because they can't do anything for themselves. You've got to feed them, you've got to bath and everything 311.6 when I see my residents all are in bed, they're in bed and can't move this, and I feel sorry for them. That's the main thing. I feel sorry for them, they are in bed, can't move, hard to—if they do poo and there's—I mean like poo and anything, it's hard, they can't move—yeah—pain here, pain there, I feel sorry for them but we have to do it	
301.4.2 Also, it's very hard for them to lose that independence so we try to keep that independence letting them still do things that they can'301.7. Having them doing things that they used to do before they came into the nursing home so that they don't think they're coming here and that's it, you know. 301.29 A lot of them it's hard for them to know they can't be independent any more so helping them out on anything. .. Just to be there for them, that's all they need	11. Individuals receiving a palliative approach are unable to do anything on their own. 12. People do not need to maintain their independence if they are receiving a palliative approach.
101.7 You've got to have an understanding of what they're going through, they can't speak for themselves 202.14 when you start it, so many changes coming, so you are more understanding. So, what is exactly going on. When you, elderly people, the situation comes, is very hard, it's not easy, so you learn, we are getting old too, it happens, so this means experience, experience 301.8 .. getting to know what they're been through so you know yourself what to expect 301.9 Not understanding what a patient's going through ... It's very hard when you're trying to help someone but you don't know what they want or need 301.12.2 .. getting to know them, what they've been through, their experiences, where they're from. It's a lot you learn from them. 301.12.3 You might think that they're silly or whatever, but they're not, they're very	13. Understanding what a person is going through as they approach the end of life helps me provide a palliative approach.

smart people 301.28 No one knows what they're going through unless you're there. So, sometimes it's hard for us to understand what they are going through because we don't really know. Unless you've been through in their shoes then you—you realise. So all we have to—we try to do like nurses here mostly we just try to be there for them. If they need someone to talk to we're there and that's all we can do I guess. 104.8 understanding the patients attitudes, because sometimes, they can be rude. That's the hardest part, just how to handle them 104.9 I think that the more I get to handle different kinds of patients, residents, understanding them better across the years has taught me to understand their attitudes	
101.62 A lot of them here appreciate being told the truth, uhm, I have a rapport with certain ones where I can piss around. Other ones I have to be very careful.	14. Understanding what a person is going through as they approach the end of life helps me provide a palliative approach.
305.11 … the only thing we can do is make him comfortable .. The only thing is change them, he talks actually, and just make them happy, that's all we can do, isn't it 102.3 Uhm, to keep them comfortable, to make sure that they are turned but not excessively, at that stage of their life, just to make sure that they are comfortable. I do not believe in feeding them, uhm, I believe in doing their lips, uhm, sponging them down, but not too much activity. Basic, just leave them alone type thing, that's my belief, and it has worked for me in the past 102.38 Don't touch them, don't feed them, don't—put Vaseline on their lips, don't—you can give them a little bit of ice, an ice cube or something for the first stages. But when it's starting to get really bad right at the end, you just make sure that they're clean and washed and all that. I honestly feel that—because I've watched this and I've	15. In a palliative approach, it is best to give minimal care.

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103.3 I think you need a lot of patience, you've got to be nice and gentle with them, you know, just a lot of care, you know, just treat them like your own, I do anyway, treat them like your own. Like how your parents would like to be treated, not pushy, rough, you know. 103.14 I think my patience, I give everybody a fair go, I don't judge, you know, I was there one time, you know, we all have to start from the bottom and learn, so don't be as mean to other people just cause they don't know how to do it, or they're not as quick as you, you know what I mean, so I think a lot of my patience and understanding 104.4 try to help the residents as much as they could and have more patience and understanding what the resident is undergoing and also, always put their feet on their shoes so that they know how the resident feels and how can they can manage to	17. A caring and compassionate attitude is essential in a palliative approach

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104.14 I'm a person who has a deep sense of understanding about the residents and I work hard just to make them happy and make them comfortable

104.17 (Be) physically strong and also emotionally strong. Don't be distressed by the things that they say, and also you need a lot of patience, and understanding

105.4 .. a lot more nurses need a lot more understanding .. a lot of people are jumping in with not the right attitude...you've got to have compassion, there's got to be a bit of compassion. I mean, I'm a hard person but you've still got to have compassion. And, if you haven

t got compassion for these people, well, you're in the wrong industry.. .it's a job, that's the attitude now, it's just a job. I'm here for the pay and it's slip, slap, slop and I'm on to the next one. And I don't like that. It's got to be a lot of one on one caring,.. it's hard to do without getting too attached to the residents because that can backfire on you too but .. you need that compassion more than anything else and if you're not going to give that, don't be in the industry.

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107.10 I believe that is for choose to do this type of work for one, you should have a lot of patience, understanding and to get to know that person. That's the way I look at it, it's important for a job like this. And a lot of patience with them and just follow up on their charts and see what's wrong with them, get to know the person, pretty much that's it

107.23 you do need to have a lot of patience and you do have to realize that they do need your help

201.15 Personal skills ... Patience, empathetic, positive attitude ..I've learned to be a better human being. Uhm, not to lose my patience more often

201.20 For a palliative approach you must know what condition the person you're looking after is in and you should be really gentle towards them. You should be empathetic towards them

201.24 everyone will benefit from a palliative approach because all you have to be is really gentle, be patient with them, understand where they're coming from, what their needs are

202.10 Just respect them, dignity, look after them properly. It's their home, not bullying them, just gently handle them, talk with them nicely, look after them, just like our own parents, so, just like our family

202.16 I'm just kind with them

203.13 I think the elderly people are more vulnerable and this age they need our love and care, you know, and a bit of attention, you know. That's why I like to do this aged care, you know, because I love these people.

203.14 I am more caring now and more understanding because all the time now I can see these people, all the residents and I learn a lot from them

301.47 Some of them had hard lives before they came here and then some of them were hardworking. Just knowing that I think makes you appreciate them more in a way and makes you think of yourself you know, what's going to happen to me if I do this or that. I think just the experiences are very interesting to listen to

301.49 you know this person's not a bad person because this person's hitting someone. You have to think there's something wrong with them and I think that's—I always try to separate those two ... It's very sad just to know what they've been

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301.62 Just to have a heart I guess you know how you will look after your own parents is how you look after these people. You always think these people can be your parents you never know what's going to happen to your parents. So to treat these people like how you treat your parents that's the best care you can give them

301.63 You're respecting them. You're not just going in there saying get up. You're respecting them and they respect you back if you do that. Just to be kind to people, we're all human beings, we all need that love, that care. So I think just to be kind to them

303.2 My approach would be a caring and understanding approach because it's that time when the client and the family needs most from us nurses and mine would be very friendly and confidential

303.20 you have to be understanding, you have to be very, very calm, like I said before because, I guess, it's that time in every one's life where, you know, a lot of support is required from us nursing staff

305.9 giving them respite, giving them love

308.32 one of them is when you sympathise the patient because medication will help, but not really anymore because they actually in palliative care

102.5.7 Plus, you need a big but a hard heart, that's how I feel about it.

102.11 I know in my own heart that I care for them. I know that I do look after them and give them the best that I can do. So, yeh, I know, I enjoy it and they enjoy me too; I can be tough, I can be rugged, I'm not the most politest person in the world, sort of thing, but they respond to me and that's what I like

309.15 Caring. If you care, everything will go right. If you just have a bit of feeling. I think to be a nurse you have to have a heart. If you don't have a heart this job is not for you .. That person can be your parent one day, that person can be you one day. So

caring, everything is caring 310.19 Another skill would be caring, because if someone came here when they didn't care then they're not going to have a good time working. You'd have to be able to care about them and that's in your heart 311.19 Like we have freedom, like we're going everywhere. For these residents, they don't have outings, freedoms, nothing. So let them be like us too. Just make them sit outside, have some sunlight, have some fresh air and everything, to make them happy and proud of themselves 103.49 You've got to be more conscious and you've got to be aware that they have certain needs or more needs, compared to other residents that are more mobile and you need to do more rounds and more personal care. Yeah, just to make sure they're always comfortable, not just shout at them, see you later. Just be aware and more conscious that they need more attention from you.	
303.17 I speak one other language, and I think that would be a good skill if I did have an Indian or Fijian client, and other than that I think I am very helpful and fun loving 310.23 understanding the resident's life; having an understanding of their life and how different it is for them being in this nursing home	18. Understanding a person's attitudes, beliefs and culture helps me when I am providing a palliative approach.
101.13 Whether it's someone in here, or someone out on the floor, uhm, and just for that brief period of time you forget about who you are and where you're from, and it just makes you feel good. 103.11 I feel better when I go home and I've done my job properly. I don't go home thinking I should have done this, I should have done that. I'm happy with what I've done every single day and I try to do my best even if I don't feel like doing it cause sometimes you don't when you're tired or whatever, but I feel good that I've done something good and come into work and done my job and I can go home with peace of mind	19. I make a difference to a person's day when I provide care with a palliative approach.

104.11 whenever you help some other people and they appreciate what you do, it gives a feeling of, oh, I did something even if it's just a little thing. They appreciate what I've done. That's the best feeling you can get
105.12.2 So, it's definitely the residents, they make your day, even on your worst day, a resident can say something to you and that just sparks you up, even the worst ones have their good days.
105.15 the way these people react to you, their response to you. You know, you'll have a bad day, and they'll just say something and you think, God, life's good
202.24 This morning, like one resident, I shower her, so she said you are a very nice lady. I said well how, how you know, she said before I was scared with you but now I'm not, I'm very confident with you, you always will listen to me, you're always comfortable with me so I am very happy
301.4 just to be loved I guess. That's the greatest issue.... but I think just to have someone to love them, I think that's the biggest issue that they have
303.16 when I feed them or give them personal care, I feel good because I feel I've made a difference in their lives
309.21 when I walk out of this door I feel so happy and I'm pleased I made a difference in someone's life. I know they can't do anything for themselves and I know at least I've done everything for them. It's a good feeling

Category 2: Physical Symptoms – Assessment and Management	Statement
101.31 if a person's sick we go to them ten times a day, we figured out that a cost of a human life here is only two panadol, coz nine times out of ten, the RN'll [say], yeh, they'll be alright, just give them two panadol 103.36 ..in nursing, as everyone knows, is based on hierarchy and who am I, I'm just an AIN. .. I'm the one who's looking after them. I think I should have more of say and an input on how that resident should be looked after because I'm the one looking after them, I'm the one spending all the time—all day, eight hours while they're (RN) only coming to see them for two minutes to hand them out medication.. 308.73 They (referring to the RN) do ask: how much is your pain, basic, you know what did they learn in university, like how much is your pain, tell me where is your pain, can you please describe your pain, simple that's it. But if you actually go there, talk to them, if you have time to communicate with them, you show them that you're there for them 102.4.1 . I believe that pain relief is probably the best, yeh, pain relief. Definitely, the best.	1. I have a role to play in pain management
103.34 The suffering. Yeah. What I've seen? One was recent who went on palliative care, and he was given a very small amount of morphine but because it was PRN no RN will like to initiate it, or put it as if they're the one giving it, it's going to make them go quicker. I think that that's prolonging their death, keep them comfortable. He wasn't eating; he wasn't drinking and that went on for over a week. That's to me, that's very cruel and that's not keeping them comfortable. ... When you saw them two minutes ago, okay maybe when you gave them the medication—say the morphine wasn't due at 12, then the next ones not due at six and what if he's really agitated then or he doesn't seem very comfortable, what's the harm in giving them and keeping them comfortable, that's what I thought palliative was. Not keeping them going and going, it's just supposed to be comfortable, but they	2. Pain medication should only be given when needed in a palliative approach.

don't do that 103.35 .. only the ones that the doctor said give, but if he seemed more agitated at the times when you think he needed more they wouldn't give him any. The PRN that was ordered and that was just never given to him. To me I think that was cruel because he was in a lot of pain	
102.43 . . I really believe that pain relief is the way to go with them. I mean you don't want anyone to suffer do you? I certainly don't. Definitely don't want anyone to suffer 305.22 when you see them suffering .. the residents, we had a resident here who was fully blind, what do you do, it's not easy to work in a nursing home, really, it's a stressful job 309.17 That hurts me every day, every single day, especially when you see them suffering. They should not be having suffering. They're in pain, you can see their expression in the face that I'm in pain, even if they have morphine, especially when you know they're going and everything. It's like you're feeling it	3. Easing suffering is usually not possible.

Category 3. Family Support	**Statement**
102.50 And once you explain that to the families they think, well yeah. Even if they're not Christians or believe in God or anything like that they really think, well yeah. It's just explaining to them 102.51 .. it's prolonging their (pause) what's the inevitable. I mean they're suffering, the families are suffering so just try and relate to what we're saying. Think of us, we're the nurses we know so it's whether the families can adapt to it. But I think if you explain it to them the best way you can, then they'll go with you 103.9 you do become a better person for it, you know, you understand, try and understand what their families are going to go through and you can try and support them by helping them understand that it's better for them, that they're not here, you know that they're gone. No more suffering 103.39 I feel more confident now that I have more knowledge of what processes are. I don't understand how they feel because everyone's different, but I think I'm more educated on trying to explain to them what's happening with their loved ones at the time, on that specific time 101.43 certain family members, uhm, how do I say this without sounding rude they expect too much of their family members. A lot of them believe they're going to get better and walk out of here and no-one sets them straight. That's how they come across to us	1. In a palliative approach, families need my support
301.25 We talk to a lot of families about anything and we listen. Most of the time all we do is listen. We don't want to say something to—that is wrong, so all we do is listen and a lot of them appreciate just listening 301.26 we refer them to more professional people than us that know better than what we know, like about certain things that their mother or father is going through.	2. I prefer to ask other team members to talk to families about difficult issues.

101.3 the residents themselves are fine .. it's the family understanding the issues around the residents .. that's where a lot of conflict comes in .. when you've got a family member whinging about this and that, the whole thing circulates about, especially in dementia, cause the families come, get amongst them .. they don't understand 101.21 where they want to keep them alive, you know it's in their care plan, they don't want, the family might not want nothing to do with it, it might be a guardian, or the guardianship, or power of attorney 101.5 I'd want an understanding of what the family want, so if it was a case management and it was my resident I'd want to be there too, so I'd know what exactly the family expected and then I knew what was expected of me 102.5.4 I feel, you've got to approach the families as well as knowing the residents 101.43.2 The expectation of what going to happen, the family aren't informed enough about the nature of the disease and what's going, what's going to happen to them. There are these sites and groups that, but if they don't want to know, they're not told either. They need to be told 304.17 non-understanding family members and that, where they come in to a nursing home and they think that they're going to improve and that, when half the time, a lot of them don't 301.24 .. what their family member is going through because a lot of them don't really get what they're going through or they don't want to know what is happening. It's hard for them to go through it alone 301.13 .. family members being on our cases all the time, and I know it's hard for them to understand what we do	3. Helping families understand what their family member is going through helps them cope better.
101.6.3 the family would be told you've either got to do this, or you don't come, especially in our area, it's alright if someone's in bed and they're dying and they come	4. Families should leave care to those paid to provide care.

in, they cry and hold their hands. A lot of the time it's family members you don't see, for so long, so it's just guilt, that's why they're here, you know what I mean
102.5.3 You have to be very strict too with the families, uhm, I feel, because you'll have people especially siblings who
ll come in, they'll wanna wet their lips and give them ice, because they know, you know, it's cruel, especially at the end. All they want to do, you know, they gotta give them some sort of fluid or things like that, but that's even worse for them

Category 4: Social Care	Statement
101.3.4 other than that, routine, repetition, it's all about making our job easier and their lives a lot better, so 101.29.3 That routine allows them to enjoy what time they've got left, you know, whether it's shower routine, meal routine, toilet routine, but because we've got so many people here, you need that routine anyway, you need to be able to have a regimental system. By having that system creates time to do other things 101.62.2 there's that many residents, they're all done by two o clock and at the end of the day, very little arguments now, very little incidents 104.12 Sometimes just dealing with residents attitudes, it's just sometimes they don't appreciate what you do and they sometimes try to tell you different things and when you do something and they don't like what you do, it's just that they don't appreciate that much, some of them 201.18 you're here for them, to look after them. And you have to do whatever they want, whatever is suitable for them, not what's in your interest 201.5 Come with a positive attitude and care for the ones you're looking after. And, care for what their preferences are 301.61 I'm thinking okay I should do that like this and they give you good advice some of them. 305.74 .. individually everyone's different, so it's good to give them education about this more often, how to care and what to do and how to make them comfortable 305.2.2 the only thing as nurses we can do is to make them comfortable, you know, we can do our best, like repositioning them, make them comfortable 301.5 Uhm, just more understanding of it, I guess and more understanding of what	1. Providing a palliative approach based on an individual's wishes improves their quality of life.

the patient likes and what they don't like 301.5.2 .. like just to get to know the patient before you attend to them, just taking that time, I guess, to get to know the patient.	
106.7 give them high care, give them as much as I can, you know what I mean, as much as I can. Uuhm, write everything about the changes in the skin, wash them, we shower them, change them, we do as much as we can for those people because they need a lot 301.1 to look after that person to the best that we can, basically doing everything for them cause they require it more than others, basically cause they can't do it for themselves. 309.1 they're the people that actually need your care more than anyone, and especially the ones that can't actually do anything for themselves, so needs a lot of caring and support too 309.90 You've got a bed bound resident in palliative care they need more attention because they can't do anything for themselves. You've got to feed them, you've got to bath and everything 311.6 when I see my residents all are in bed, they're in bed and can't move this, and I feel sorry for them. That's the main thing. I feel sorry for them, they are in bed, can't move, hard to—if they do poo and there's—I mean like poo and anything, it's hard, they can't move—yeah—pain here, pain there, I feel sorry for them but we have to do it	2. Individuals receiving a palliative approach are unable to do anything on their own.
301.4.2 Also, it's very hard for them to lose that independence so we try to keep that independence letting them still do things that they can'301.7. Having them doing things that they used to do before they came into the nursing home so that they don't think they're coming here and that's it, you know. 301.29 A lot of them it's hard for them to know they can't be independent any more	3. People do not need to maintain their independence if they are receiving a palliative approach.

so helping them out on anything. .. Just to be there for them, that's all they need	
101.7 You've got to have an understanding of what they're going through, they can't speak for themselves 202.14 when you start it, so many changes coming, so you are more understanding. So, what is exactly going on. When you, elderly people, the situation comes, is very hard, it's not easy, so you learn, we are getting old too, it happens, so this means experience, experience 301.8 .. getting to know what they're been through so you know yourself what to expect 301.9 Not understanding what a patient's going through ... It's very hard when you're trying to help someone but you don't know what they want or need 301.12.2 .. getting to know them, what they've been through, their experiences, where they're from. It's a lot you learn from them. 301.12.3 You might think that they're silly or whatever, but they're not, they're very smart people 301.28 No one knows what they're going through unless you're there. So, sometimes it's hard for us to understand what they are going through because we don't really know. Unless you've been through in their shoes then you—you realise. So all we have to—we try to do like nurses here mostly we just try to be there for them. If they need someone to talk to we're there and that's all we can do I guess. 104.8 understanding the patients'attitudes, because sometimes, they can be rude. That's the hardest part, just how to handle them 104.9 I think that the more I get to handle different kinds of patients, residents, understanding them better across the years has taught me to understand their attitudes	4. Understanding what a person is going through as they approach the end of life helps me provide a palliative approach.

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102.11 I know in my own heart that I care for them. I know that I do look after them and give them the best that I can do. So, yeh, I know, I enjoy it and they enjoy me too; I can be tough, I can be rugged, I'm not the most politest person in the world, sort of thing, but they respond to me and that's what I like

309.15 Caring. If you care, everything will go right. If you just have a bit of feeling. I think to be a nurse you have to have a heart. If you don't have a heart this job is not for you .. That person can be your parent one day, that person can be you one day. So caring, everything is caring

310.19 Another skill would be caring, because if someone came here when they didn't care then they're not going to have a good time working. You'd have to be able to care about them and that's in your heart

311.19 Like we have freedom, like we're going everywhere. For these residents, they don't have outings, freedoms, nothing. So let them be like us too. Just make them sit outside, have some sunlight, have some fresh air and everything, to make them happy and proud of themselves

103.49 You've got to be more conscious and you've got to be aware that they have certain needs or more needs, compared to other residents that are more mobile and you need to do more rounds and more personal care. Yeah, just to make sure they're always comfortable, not just shout at them, see you later. Just be aware and more conscious that they need more attention from you.

303.17 I speak one other language, and I think that would be a good skill if I did have an Indian or Fijian client, and other than that I think I am very helpful and fun loving 310.23 understanding the resident's life; having an understanding of their life and how different it is for them being in this nursing home	8. Understanding a person's attitudes, beliefs and culture helps me when I am providing a palliative approach.
101.13 Whether it's someone in here, or someone out on the floor, uhm, and just for that brief period of time you forget about who you are and where you're from, and it just makes you feel good. 103.11 I feel better when I go home and I've done my job properly. I don't go home thinking I should have done this, I should have done that. I'm happy with what I've done every single day and I try to do my best even if I don't feel like doing it cause sometimes you don't when you're tired or whatever, but I feel good that I've done something good and come into work and done my job and I can go home with peace of mind 104.11 whenever you help some other people and they appreciate what you do, it gives a feeling of, oh, I did something even if it's just a little thing. They appreciate what I've done. That's the best feeling you can get 105.12.2 So, it's definitely the residents, they make your day, even on your worst day, a resident can say something to you and that just sparks you up, even the worst ones have their good days. 105.15 the way these people react to you, their response to you. You know, you'll have a bad day, and they'll just say something and you think, God, life's good 202.24 This morning, like one resident, I shower her, so she said you are a very nice lady. I said well how, how you know, she said before I was scared with you but now I'm not, I'm very confident with you, you always will listen to me, you're always comfortable with me so I am very happy 301.4 just to be loved I guess. That's the greatest issue.... but I think just to have	9. I make a difference to a person's day when I provide care with a palliative approach.

someone to love them, I think that's the biggest issue that they have	
303.16 when I feed them or give them personal care, I feel good because I feel I've made a difference in their lives	
309.21 when I walk out of this door I feel so happy and I'm pleased I made a difference in someone's life. I know they can't do anything for themselves and I know at least I've done everything for them. It's a good feeling	

Category 6: Social care	**Statement**
305.48 it's more sad just staying in bed, lying down, doing nothing. You have no other options. You can't do much. At least if you just move out, it would be good. It's good for your brain	1. In a palliative approach, I think about the person holistically.
305.53.2 Would be good if there will be changes in there, like have activities and stuff like that. Not to just stay in the room and stay there.	
305.56 It's good .. you feel good, you feel different. The environment is not just staying in there, in the room, and knowing that you are dying ..—if you take them out, probably refresh their mind .. you feel good	
305.66 I would—to make them feel as not a person in the bed	
309.55 So mainly basically they need one on one. If I'm sitting in a room 24/7 and doing nothing, I'll probably get depressed too. So one on one is the best	
310.34 .. like bus trips, when they go out they go to far places, they see (like)water, they see the big lakes and grass and that's not something they see everyday .. they just sit there and they have their tea or ice cream but . what I love is, when they come back they have more energy, it's like they've gone somewhere, their eyes have opened and they come back and they're better, they're nice to you, they're in a good mood. They're joyful.	
310.41 the way I care about them is I'll push more time to talk to them, I'll make sure that I have to go back to them and talk to them and see how they're doing .. I'll come back, when I have time, I'll go and quickly say 'hello', and how they're doing	
311.18 They always are staying in bed, like them, like out of bed, have	

some fresh air outside and have sun, make them happy outside to see surroundings 311.24 I go to the resident and she likes reading story books. Then in my spare time, if I have nothing to do, I have to spend time with my residents. So when I go with her, I just read with her, share with her what's in this book, and make them happy. Also like I'll ask her about—other residents like watching TV and there's a favourite program like maybe *Home and Away*, whatever. I tell them a story about them and all this to make happy so that she can refresh her mind	
308.47 spending time sitting with the patient, talking to the patient, even though, the patient isn't responding, he can still hear me though. That's the last thing, one of the senses to be active, so then he will feel that there is someone who is there for him or her. So it's better if you have time to sit with the patient.	2. Spending time with a person who is approaching the end of life is important.
101.11 at the end of the day generally, out of a week, I'll go home thinking I've made a difference three out of five days, so it's still worth it 106.16 when someone's crying and feeling really bad, and not happy and I try to talk with him, make him calm down and make him happy and he starts laughing, that's the best feeling 106.14 When you work more and get more experience, and you feel better when you're helping those people. Like, really, they need help. When you help someone and you make him happy, they're touching you, you know what I mean. You feel good.	3. Caring for a person with a palliative approach is rewarding.
103.42 Yeah I've learned more so that's what I meant, I don't feel guilty. I don't feel like it's just a job, like some. It's not a piece of paper	4.

it's not a piece of meat that I was dealing with, it's a person, it's a human being. I feel like if I've done everything that I could on that day for them that I don't feel guilty when I go home. I feel good that I've had a good day and I've probably made their day or that little bit happier for them on that day, so I feel good if I can offer the best I can'107.15 I'm very fulfilled coming here. I'm happy when I see they're happy. That makes me very happy. I'm very emotionally attached to a lot of them in here as well. Very emotionally attached which you shouldn't be, but I am. But, it gives me a satisfaction knowing that I can help them knowing that they can't help themselves. That's the way I feel about it	
108.14 when I'm caring for them, just feel very happy and I like to talk with them every day because they're also very happy to see me every day.	
201.12 At the end of the day, you know that you've done something good, you've looked after someone. Yeh, it makes you feel happy	
201.14 you know you've helped someone in some way. The ones who can't really look after themselves. So, yes, it makes you feel good. Makes you proud	
202.10.2 your heart is also devoted to what you are doing. It is very satisfaction work as well. I know we are all working for money but on the other hand, you have to be kind hearted as well, and feelings ... mentally and consciously I am very satisfied what I'm doing. My hands working for someone, so it is worthwhile.	
205.19 When I see a resident who maybe at some point they were depressed and they've come out of that whether someone's spent extra time with them or some reason, when you see that smile and	

their face. When you see the change, yeh, that's rewarding 305.24 , I love elderly people back home is we're brought up different way ... looking after my grandma, my aunties, uncles, always [being] respect for them, always loved looking after old people, I love looking after elderlies 305.71 One side is a job and another thing is I want to do it. Or else I would have left this job ages ago 308.51 They can see that we treat the mother very good as a family, it's not just we're here, we're being paid, we're working, we're here to take care of them as well and it's not all about money, it's a commitment and passion we need to be here	
305.70 it's the work I do as a nurse, that's my responsibility, that what I should be giving them, the love, respect and dignity. That's my job too and I have to do that 308.9 I reckon that's the needs that they wanted to have, emotional, communication—that's one of them. If you talk to them, you'll actually learn what's going on (sic)to the patient 308.11 we dress them, we shower them, we feed them. Physically yes, mentally we give them medication, but emotionally, spiritually, they don't have that. Maybe I reckon that's the lacking that we don't have to offer them 309.8 Helping them for everything, to be honest. Mainly they need everything. Once they come to a nursing home they need their toileting, they need assistance with food, they need to socialize, they need support, Sometimes they can easy go into depression so they need someone to talk to because the family members sometimes don't all come. So we are their family, we are their carers, we are everything	5. Identifying a person's emotional, social and spiritual needs is my responsibility.

for them, actually everything like personal care, assistance with feeding, toileting, emotional support, everything 309.9 Just being there for them, showing them you care. I think that's more important. If you just listen to them. Sometimes if a resident is asking you something all they want is to be listened and get what they want. So if you listen to them and you will be able to understand it and they don't feel left out .. If you just listen, you go and do it, she's really happy with that. So she's satisfied listening to them, what they want. That's going to improve everything 311.3 they need their family to be there, that's the main thing I would say, the family. For them we are the family, we have to do everything for them as like daughter, brother, son or daughter in law like too. Make them as much as happy we can, so that they are satisfied for everything .. You think like it's our parents and the parents—we help doing our parents—so we don't have to ignore 311.25 Some of the residents like knitting and all this. They love that. Spending time with them… sometimes we learn from them too. While we are spending time with them we can learn from them what they are—staying with them, whatever, so that we have more—we're learning from them as well	
308.52 respect, dignity and care, are the most important things for palliative care patients and it's just like it doesn't mean that person is dying, they're not considered as a person, you know, that's alright he's going to go anyway, they'll be fine, you know those things, there not really a good thing to say. But if you actually learn what palliative care is, why do you need to take care of the patient, cause really end of life and then why do you need to give them respect and dignity, it's a way of giving them everything before they go	6. I maintain a person's dignity until the end of life.

107.4 What can we do to give them more quality of life? I really don't know, well, what I do is I befriend a lot of them, listen to their stories and things like that. I do a lot of things like that for them. Just to make them happy for the day while I'm here, that's about it really. I can't do that much else.	7. I provide more than physical care when providing a palliative approach.
107.8 you've got to give them just a little bit of hope so that they know just because they're here doesn't mean it's the end for them. So, that's where I come into it, where I like befriend them and, like I said, listen to their stories, or things like that really, that's about it	
204.7 Make them feel like a human being, not just they're sitting on a bed. It's alright they're going, like, they're passing soon. Make them feel like family member, take them out and let them sit with other residents, not just leave there in a room	
308.27 It's not just physically doing it, just to give them satisfaction. Of course you have to have mentally—you have to be mentally stable as well, emotionally stable	
308.32 as assistants in nursing, we should give them comfort, sympathise the patient—that's what we do as well. We give them needs. Whatever they want, just give it to them just to give them happiness for certain days	
309.74 It's really important because all you can do with the residents is just change them, bath them, shower. So you don't have time to talk to them, you don't. If you keep—at least if you sit down half an hour with them that means someone else is missing a shower or someone else is missing a change. So there's like this you're just going one on one, you're next, you're next, you're next.	
309.88 You can't give them sometime anything to drink or eat	

because they're not tolerating and they can't swallow that. Just holding them hand. Holding them hand, that's it. Nothing—what else can you do for them	
205.8 our attitude as well, our disposition and I know I haven't been doing it for very long, but I know when you carry a smile, you transfer that 309.50 always smiling because dealing with dementia people if they see you're cranky that's where they're going to get cranky. So you always need to put a smile. Even if it sometime gets to the point when it's really hard .. Always got to smile. You happy smile in front of you even if sometime you're so emotional and stressed—always—if you go in someone's room and you've got a smile on your face, automatically they're happy, they smile too 310.6 just to stay positive toward the resident; try and not get angry or be negative towards them—being loud or rude. 305.83 For patients like palliative cares—to be a nurse you have to have patience, I would say. Because especially working in aged care, it makes you angry and things like that, but—because you have to understand. You have to love your job to do things like that. If you don't like your job, if you don't love your job, you shouldn't be working in a place like that. You have to have patience. I would say you shouldn't be in this [field] 306.8 we have to understand, my opinion in this stage is this is final stage for everyone, not can avoid this stage. So we have to be patient for these people and, uhm, do your best. 308.49 It's very helpful for me if they remember me because if I tell them to roll, they roll, cause they remember my voice. Those things, if	8. A positive attitude is helpful when providing a palliative approach.

you gain someone's trust, then it's easy flowing … if a family member or even a resident actually, if you've already gained their trust, it's not hard to explain what you're going to do and then they will give you trust, you know. It's just like a family, if you treat them as your family then they will treat you as family as well. So they're not going to give you a hard time, if something happens to them they will let you know, you know, it's basically they're not afraid of you. You gain their trust, it's like in a family you don't have a problem attending them	
310.10 Patience—just to be patient with the resident. To approach them being calm and nice. Like I said before, not being loud	

Category 7: End-of-life care	Statement
101.28 on the fourth day, seven minutes to one, actually, I was in there about ten to one, he started to groan. I said, 'it's alright mate, close your eyes and have a big sleep', put his hands on his chest; I just closed his eyelids and he took his last breath but he went quietly, pain free and with dignity. You can't ask for more than that.	1. I am able to provide comfort when a person is dying.
102.6 I just think keeping them comfortable; Just mainly keeping them comfortable, think.	
102.23 mean we can't be angry and we can't give them—sometimes we have to give them that bit of authority, the way we approach them. But when they're sick and they're dying all they just need is just tender loving care. Just that hands on, that touchy feely. If they haven	
t got any family they don't want to die alone. They don't. So just touching them and being there with them	
102.32 It's not just going making sure that they're being washed and clean and all that; it's going in there spontaneously just to make sure that he's all right. Just to give his hand a touch or his forehead or something like that just to know that we're there. He doesn't have any family anyway, so he's been alone for a long time. So I think he likes that ... I think just going in there and just making sure that everything's fine and they're clean, they're dry. And he knows that we care sort of thing. You've got to make sure that we know—that they know that we care, that somebody's out there looking after him sort of thing	
308.20 Before palliative, for me—it's just .. a dying person. Just give him comfort—make him comfort. But other than that, you have to know the value of it. You have to give them time and effort. Giving	

comfort as well is to communicate with them. Give them whatever they want because they won't have that wherever they're going to. So palliative for me—they have to give—.. they should give more nurses for that person, though, to attend that person needs.	
101.8.3 When someone goes and they're your resident, you do feel cut, but, you try, or, I try and [dissociate?] myself from the family members, they don't see me upset, I don't want to upset anyone 101.9 I was keen, you know, and I got real close to a couple, then they died, and I sort of went cold 102.52 You've got to be tough but you've got to be—I don't know, I've just learnt over the years to… You have to turn off. I think you have to turn off, you've got to be really strong otherwise every time someone passes away; if you start crying each time it drains you too. You don't become that nurse that you wanted to become. You do get attached to them, and you really think—but you've got to be tough, you've got to be cruel to be kind 103.8 The end part, yeh, when you know they're going to die and you've been looking after them for a long time. They tell you not to get attached but you do, it's just part of life, you know, but it's just hard to see them suffering, yeh, you just want them to end quicker, you know. 105.10 they can be the worst resident but if they're in that stage, you can't help it, it's very hard not to get, you know, emotionally involved, then, you've still got to say good bye and at the end of the day, we've still got to walk out of here, and then you come back the next day and think, well, is Mrs Smith there this morning 105.11.2 this is going to be great, I love working with the old people, and then the bonds come and you don't expect that and it's like a	2. I am able to manage my own grief when a person I have been caring for has died.

whammy when you lose a resident or something, so I think that in time you become more prepared, you prepare yourself better for it.

106.15 sometimes, you get upset about those people, they've been here so long and one day, you miss them, they're gone. That's the life but, we get upset a bit but you have to change cause you can't continue

303.10 to lose a good client would be very hard if you had that relationship and, suddenly, one day you walk in and he or her is not there. That would be a bit difficult

305.9 we're so attached to the residents here, we do feel sorry when they're in the last stage, they're dying you know and things like that, you feel it

309.18 sometimes I cry, to be honest, to get that out of me. Even then you still have to put that aside, just go and look after them, care for them and that. But that is the hardest part ever because you get used to them. I know they do teach us not to get attached to them. How could you not?

309.37 If you see someone grieving, talking to someone. I normally take my grief and go home and talk to my husband. Or I'll talk to a friend. Just get it out of my chest. So it's—the best is just to talk. If you keep it inside of you it might eat you slowly. It is, it's really emotional, especially you're looking after—you are more with them than you are with family members. So it is emotional

309.40 every nurse that deals with end of life something at least one a month to have a counselling. That will help a lot, I can tell you that. So you go to—talk to someone you don't even know at all and it will help you

102.45 .2 I don't know I just think that all I want them to do is to go. .. It's terrible to see somebody—and it's slow agonising death. It's not quick. These people that die instantly or die quick, that d be great but unfortunately there's not very many that just die in their sleep is there without suffering a bit of pain 102.52.3 Whether you're close to them or not, seeing someone pass away is not a really good thing. I feel anyway. Personally I mean I hate it. I hate the thought they've got no-one, so we're the last people they see or they feel or whatever. 202.71 because always I scared when somebody—even if I see somebody when I was young I can't sleep the whole night. When you was young and all married so that's different but when you are getting old then you go it's all right, this is part of our life. 303.11 I think I've become a bit stronger, yeh, after seeing them suffering and going through so much pain and all that. I think when I started I wasn't as strong as I am right now. So, you have to be strong to provide end care 308.17 it's not because I'm scared of taking care of a person who's actually in a critical condition or palliative situation. It's just I sympathise , empathy is, (pause) it's really hard for me to see them like that. It's not because I don't want to see them like that. It's just—I don't want to say I feel sorry because it's not really a good term, but I don't like people dying. I don't want to see them dying. 308.60 it was very hard for me when I just started but I had to cope with it because it's part of my job .. I had to cope but right now it's alright but I don't want them to die in my [unclear]hands, that's the main thing, no, I don't feel like it	3. I am not comfortable caring for a dying person

308.62 ..because I treat them as a family it's very hard for me to see them going. So, that's me. It's very hard for me	
102.52.2 but I think you just need to be quite tough. Get on with the job. Do what you have to do. Put them in the body bag. Then after that then there's a sigh of relief, saying ah that's done. 304.17 Dead bodies... And, having to deal with, like, when someone passes away, cause you've looked after them 103.38 the first time that happened to me that somebody had passed away, what do you say? I've never really—I came, I did my job, I didn't try to get really close to their families, or try not to do that with the residents, but you can't help it. Over time, it's a natural part of life I think. Just being there for the family and listening to what they have to say. Just to comfort I think, if they want to talk obviously they want to say something, otherwise they wouldn't. So just being there I guess, where before I was just, run away I don't want to deal with that	4. I am not comfortable with the care of the body when a person has died
201.9 One thing is depending on what situation the resident is in, that you're looking after. Like, sometimes, if you're attached to someone, and they're really sick so you've got that emotional bond. So, that makes you feel sad and, obviously, losing someone 201.13 someone's behaviour. Obviously, they didn't do it on purpose, but sometimes they don't know what they're doing and, obviously, losing someone is the biggest thing 202.61 because sometimes they are just like our family when they pass away. You have to just—sometimes you cry too	5. I feel sad caring for people approaching the end of life.
301.21 What I realised with some patients they wait for someone to come, that certain person to come see them, and then they pass away. They are always waiting for something and sometimes it might take	6.

them two, three months to wait for it. Then, if that person's not here to see them, then they give up I guess.	
309.1.3 It's really hard to watch them, really hard. Sometimes it gets to you, to be honest. You go at the end of the day at home and you just look at yourself and look at your pictures and you know where you're ending up, where you're going. It's sad	

Category 8: Professional development and reflections	Statement
104.7 . If you do the things most of the time, I think that's enough experience, so that you gain a lot of experience so that in the future you know how to handle different types of residents. 106.12 when you work more, you get more experience and you know how to behave with those people, cause, we're living here most of the time, we're working from morning until three o clock, we're staying with them more than we're staying with the family, which is we get more information 107.22 I learned through spending time with them. I spend a lot of time with my residents. Like, I'll take them out for lunch or I'll sit with them. I actually do do a lot for them but I learnt that way. 301.8.2. .. That's the best way to so that you know, cause sometimes it's different reading it and actually being in it, so I think, first hand, just getting there and that's the best experience you'll get. 101.15 basic nursing is basic nursing, where ever you go, it's all common sense: if they're having a fight, separate them, if you're causing the guy to get cranky, walk out of the room, you know, it's all common sense	1. In a palliative approach professional development is not necessary when care providers can learn on the job.
302.6 nurses can learn by education as well, how to give better care to a patient. 103.18 more education, more in-services, you know what I'm mean, more education, you're always learning more, you know what I mean, you can never stop learning 105.23.2 like peg feed residents, trache residents, don't just throw	

you in. Yeh, more education on the little things to do with palliative, don't just presume … because you're an AIN you can do it 105.23 there might be some things extra that this person needs. It might not be just a normal straight out, go in, look after, change them and things like that. There might be a little bit extra or something. Make sure we've got the training and the skills to do that. Not just presume because you're an AIN you can do it 308.72 for me education is the foundation of life, so if you have more learnings, you adapt more things and then you just apply to the others as well. So more skills, more knowledge, it's easier for you to share it as well, it's easier for you to work it out how you deal with others, that's how I see it 309.34 Not quite had much education except my knowledge and I think it's just being a human being 309.64 They should because if—why is the RN need continuing education to register their registration. That should be for us too. What's different to us? Honestly—well what is the different between us and the RNs? The RNs all they do is just give medications and that—which Cert IV—we're doing that now anyway.	
101.8 People, family members, and staff, that's the hardest part. Someone dying, we're all dead, it's just a matter of time. 308.70 ..what is a minute to give them attention. You know, it's just not because you're an RN, or you're an AIN doesn't mean that you don't have time for them as well. It's just like it should be everyone in the group not only us, cleaners, whoever, anyone can have time to chat with them. While they're mopping, why not talk to them, that's what they want, they want to feel that someone is there for them	2. I work well in a team providing a palliative approach

308.77 .. without us, they won't know, that's as far as I know because we're the ones who's hands on to them, so, in aged care 310.39 ..Other hard things is .. if we don't have any support by everyone else in the workplace .. if there was no-one helping us with feeding people or just little things like that. It makes a difference because there's so much pressure on us .. but, what is hard is not having team work	
101.20 I'll tell you, we're the bottom of the food chain, the information gets filtered down through the management and RNs do the case management and the care plans	3.

Appendix 6 Item finalised for Phase 2

Knowledge Questions

The 51 knowledge items of the Knowledge of a Palliative Approach Questionnaire (optional survey) and the Content Validation of Knowledge Questionnaire (CVKQ):

1. Palliative care aims to improve the quality of life for people with life-limiting conditions. E
2. A palliative approach is when everybody agrees that providing comfort is the goal of care. E
3. When a person receives palliative care it means they are actively dying.
4. A palliative approach may be required for some people for months or years while for others it may be required for hours or days. MD
5. A palliative approach is offered when treatment will not cure the person's condition. E
6. There is nothing else that can be done for a person receiving palliative care.
7. People with advanced cancer, end-stage organ failure and dementia benefit from a palliative approach. D
8. A palliative approach can be offered to people who are elderly and frail. E
9. In a palliative approach people are best cared for in bed. E
10. Attending personal care needs is the most important aspect of palliative care.
11. The decision to begin palliative care is when everyday care becomes

hard for families.

12. Quality palliative care is individualised and respects the person's preferences and wishes. E
13. Families can experience grief before the death of their family member. D
14. Families cope better when they understand what is happening and are involved in decision-making. E
15. Effective communication is based on listening and talking.
16. The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube is because he/she can no longer swallow safely. D
17. When a person with dementia is admitted to a residential aged care facility it is because they have developed advanced symptoms of the disease.
18. To prevent a person with dementia from dying it is important to encourage feeding.
19. In a palliative approach a person can be offered food for comfort against medical advice if the family understands the risks of feeding.
20. The needs of people requiring palliative care are the same. D
21. Hospital is the best place for a dying person because the problem can be identified and treated. E
22. Not everyone involved in the care of a person with a life-limiting illness needs to be able to discuss dying and death.
23. When a person can no longer do anything on their own, it is a sign that they are approaching the end stage of their illness. MD

24. The age group of people with palliative care needs is getting younger. D
25. Explaining the purpose of your care maintains a person's dignity even when they are not responding. E
26. Frequent repositioning is always necessary to prevent pressure sores when a person is receiving palliative care. D
27. Identifying symptoms is the first step in being able to manage symptoms. MD
28. Families or carers who know the person best are usually the first to detect changes in a person's condition. E
29. Advance Care Plans can be completed when the person's disease is known.
30. Observing a person for pain provides more accurate information than pain assessment tools.
31. Pain relief before providing physical care helps a person experiencing pain feel more comfortable during care routines. E
32. Pain relief should only be given for pain that is present.
33. If a person has pain it is best to leave repositioning them unless necessary.
34. Pain can be caused by physical, psychological, social or spiritual distress. MD
35. Facial expressions, calling out and resisting care can be the result of pain. MD
36. When a person is receiving pain relief, they no longer experience pain. D
37. A dry mouth is one of the most common symptoms in a person with

palliative care needs. D

38. A family conference aims to inform the family what care the person will receive.
39. A team approach in palliative care is important because individuals and their families need a broad range of skills. MD
40. A person's wish to die means that the person will die soon. D
41. The early phase of dying can begin up to three weeks before a person dies.
42. Signs of active dying can be present hours to days before death occurs. D
43. Changes in breathing are not a normal part of the dying process.
44. Grief and loss is the last stage after a person has died.
45. If you know a person's cultural background it is easy to provide culturally sensitive palliative care. MD
46. It is better to provide information about palliative care to people from culturally and linguistically diverse backgrounds in English. MD
47. Assisting an older person to socialise with others will prevent them from feeling lonely or depressed.
48. Truthful and respectful communication improves psychological wellbeing. MD
49. Spiritual care involves asking a person about the things that are important to them. D
50. Professional development in palliative care encourages self-reflection. D
51. Providers of palliative care do not need professional development if they are able to learn on the job. D

Skills Statements

The 48 skills statements of the Content Validation of Skills Questionnaire (CVSQ) formatted in SurveyMonkey:

1. I observe what an individual can do independently.
2. I provide care according to an individual's care plan.
3. I update individual care plans based on observation of the individual.
4. I provide care in line with Advance Care Directives.
5. I provide individualised personal care.
6. I observe an individual's ability to feed themselves.
7. I safely feed an individual.
8. I encourage fluids on a regular basis.
9. I provide mouth care based on my observation of individual need.
10. I observe for problems with an individual's skin.
11. I provide comfort that an individual needs.
12. I position people for comfort.
13. I observe for pain when I provide care.
14. I ask an individual whether she/he has pain.
15. I record pain using a pain assessment tool, such as the Abbey Pain Scale, in line with care plan directives.
16. I report pain to the registered nurse or person in charge.
17. I provide non-medication strategies, such as gentle massage, in order to manage pain.
18. I evaluate the effectiveness of pain management strategies.

19. I monitor and report bladder or bowel problems.
20. I monitor and report increasing confusion.
21. I monitor and report problems with breathing.
22. I monitor and report any changes in an individual's condition.
23. I support families by addressing their concerns.
24. I communicate with families by providing information.
25. I support families when they are grieving.
26. I direct families to other members of the care team when they need further advice.
27. I report the needs of individuals to the registered nurse or person in charge.
28. I raise the concerns of (advocate for) the individuals in my care.
29. I contribute at team meetings or family conferences.
30. I communicate with doctors about the needs of an individual, as necessary.
31. I communicate with other allied health providers about the needs of an individual, as necessary.
32. I contribute to problem solving to seek solutions.
33. I support team members.
34. I recognise the signs when an individual is approaching the end of life.
35. I provide privacy for a dying person and his/her family.
36. I am attentive to a dying individual's care.
37. I maintain the dignity of a dying individual.
38. I manage my own emotional responses when a person I have been caring

for has died.

39. I maintain an individual's safety.
40. I demonstrate understanding in the care I provide.
41. I build a relationship with the people I care for.
42. I actively listen to the people I care for.
43. I am able to care for a person with difficult behaviours.
44. I reflect on my performance and attitudes when providing a palliative approach.
45. When I am unsure about how to do something, I seek advice.
46. I find ways to manage stressful situations with individuals and families.
47. I am able to maintain a worklife balance for my own wellbeing.
48. I learn how to provide a palliative approach by doing.

Attitudinal Statements

The 36 attitudes statements of the Content Validation of Attitudes Questionnaire (CVAQ) formatted in SurveyMonkey:

1. A palliative approach can help improve a person's quality of life.
2. In a palliative approach, people are best care for in bed.
3. I am unable to improve a person's quality of life with a palliative approach.
4. I am able to provide comfort when a person is dying.
5. Spending time with a person who is approaching the end of life is important.
6. Identifying a person's emotional, social and spiritual needs is my responsibility.
7. Explaining the purpose of my care demonstrates respect even when an individual is unable to respond.
8. Easing suffering is usually not possible in a palliative approach.
9. I find it difficult to care for people who are suffering.
10. Providing a palliative approach is not the same as usual care.
11. Hospital is the best place for a dying person because their problems can be identified and treated.
12. Individuals receiving a palliative approach are unable to do anything on their own.
13. I feel sad caring for people approaching the end of their life.
14. Caring for a person with a palliative approach is rewarding.

15. I provide more than physical care when providing a palliative approach.
16. Providing a palliative approach based on an individual's wishes improves their quality of life.
17. In a palliative approach, families need support.
18. I prefer to ask other team members to talk to families about difficult issues.
19. I find it hard to control my emotions when families are grieving.
20. It is best to give minimal care to a dying person.
21. I am not comfortable caring for a dying person.
22. I am not comfortable with care of the body when a person has died.
23. Families should leave care to those paid to provide care.
24. Understanding what a person is going through as they approach the end of life helps me provide a palliative approach.
25. A caring and compassionate attitude are essential in a palliative approach.
26. In a palliative approach, I help a person feel at home.
27. I make a difference to a person's day when I provide a palliative approach.
28. Seeing people who are not going to get better being fed through a feeding tube distresses me.
29. Pain medication should only be given when needed in a palliative approach.
30. I have a role to play in pain management.
31. A palliative approach in an aged care facility is not as effective as

specialist palliative care.

32. I always encourage palliative care residents to eat even if they lack interest.
33. Understanding a person's attitudes, beliefs and culture helps me when I am providing a palliative approach.
34. When I provide a palliative approach, I think about the person holistically.
35. In a palliative approach professional development is not necessary when care providers can learn on the job.
36. Sharing experiences with colleagues is important when providing a palliative approach.

Appendix 7 Phase 2 Content validation

Results of Content Validation of Knowledge items and revision of items based on expert (n=11) comments.

Item (and correct answer)	Original	Revised items	Expert comments	CVI Clarity 4, very clear 3, clear with minor revision 2 =clear with major revision 1 not clear	CVI Relevance 4, very relevant 3, relevant with minor revision 2 relevant with major revision, 1 not relevant
Instructions	**Instructions for completing the questionnaire** The purpose of this questionnaire is to learn about your knowledge of palliative care. Another term for palliative care is a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. 1. Please circle each statement True, False,	**Instructions for completing the questionnaire** The purpose of this questionnaire is to learn about your knowledge of a palliative approach. All statements concern the care of an individual receiving a palliative approach and his/her family in the place where you provide care. 1. Please circle each statement True, False,	1. Please explain palliative in plain language 2. Why not explain 'palliative care' in simple terms? 3. Throughout the questionnaire, the term palliative approach or palliative care is used interchangeably. I wonder if for consistency, using the one term would improve the clarity. Or a more detailed explanation between palliative care and a palliative approach. 4. Palliative Approach usually refers to comfort focused care	4=63% (n=7) 3=18% (n=2) 2= 18% (n=2)	-

	Don't Know 2. Please respond to all questions.	Don't Know 2. Please respond to all questions.	and may span the last 12-18 months of life in an elderly person. It is different to what is seen as ' palliative care'—which is more often about symptom management—end of life care or last days, weeks of life.		
Question 1 TRUE	Palliative care aims to improve the quality of life for people with life-limiting conditions.	A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.	1. Explain Life-limiting in simple language	4=91% (n=10) 2=9% (n=1)	4=100% (n=11)
Question 2 TRUE	A palliative approach is when everybody agrees that providing comfort is the goal of care.	A palliative approach supports comfort but does not provide a cure.	1. everybody? person for whom the palliative care is being provided, the family, the staff, the larger community? 2. Comfort care = end of life care, in the last few days. So I wonder whether rephrasing this question would help. The question is about focusing on the goal. 3. comfort is not the only goal e.g. pain management	4=81% (n=9) 3=18%(n=2)	4=81% (n=9) 3=18%(n=2)
Question 3 FALSE	When a person receives palliative care it means they	When a person is being cared for with a palliative approach it means they are about to die.	1. People do receive palliative care when they are actively dying but also when their life limiting illness can no	4=63% (n=7) 3=18%	4=72% (n=8) 3=18%

	are actively dying. DELETED		longer be treated.?? 2. Explain 'actively dying' 3. In some instances, PC is provided even when people do not have terminal illness. Its focus on QOL makes it appropriate for disabling chronic conditions as well. 5. palliative care should be provided before actively dying 6. not sure what you are hoping to achieve here because it can mean a person is actively dying but most often it means they are approaching the end of life and transitioning to that phase	(n=2) 2=9% (n=1) 1=9% (n=1)	(n=2) 2=9% (n=1)
Question 4 TRUE	A palliative approach may be required for some people for months or years while for others it may be required for hours or days.		No Comments	4=100% (n=11)	4=100% (n=11)
Question 5 TRUE	Palliative care is offered when treatment will not cure the person's condition.	A palliative approach is offered when treatment will not help the person to live longer.	1. Are we talking a condition such as an arthritic elbow or a life limiting condition?	4=91% (n=10) 3=9% (n=1)	4=100% (n=11)

Question 6 FALSE	There is nothing else that can be done for a person receiving palliative care. DELETED	There is no treatment or medication for a person receiving a palliative approach.	1. What is meant by 'nothing else can be done'? 2. Is this assuming that palliative care encompasses every aspect of care 3. ambiguous – nothing can be done by way of cure but a lot can be done by way of comfort and symptom management	82% (n=11) 4=63% (n=7) 3=18% (n=2) 2=9% (n=1) 1=9% (n=1)	82% (n=11) 4=63% (n=7) 3=18% (n=2) 2=9% (n=1) 1=9% (n=1)
Question 7 TRUE	People with advanced cancer, end stage organ failure and dementia benefit from palliative care.	People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative approach.	1. Explain what 'end organ failure' is 2. could add and a 'palliative approach'- I think both terms need to be used as they are different and not really interchangeable 3. Most people with ...	4=72% (n=8) 3=18% (n=2) 2=9% (n=1)	4=72% (n=8) 3=27% (n=3)
Question 8 TRUE	A palliative approach can be offered to people who are elderly and frail. DELETED CV(2)	A palliative approach can be offered to an older person if they are becoming frail.	1. people who are elderly and frail as well as those who are younger and in better health. 2. again yes but maybe add .....and have a limited life expectancy	4=81% (n=9) 3=18% (n=2)	4=91% (n=10) 3=9% (n=1)
Question 9 FALSE	In a palliative approach people are best cared for in bed.	People receiving a palliative approach are best cared for in bed.	1. Rephrase—People receiving a PA are best....	4=91% (n=10) 3=9% (n=1)	4=91% (n=10) 3=9% (n=1)
Question 10 FALSE	Attending personal care needs is the most important	Attending personal care needs is the most important aspect of a palliative approach.	1. a part of palliative care 2.—is often seen as the most important aspect—may be gentler and still gets	4=91% (n=10)	4= 83% (n=9)

	aspect of palliative care. DELETED		them to think but doesn't' t set them up to be wrong	3=9% (n=1)	3=9% (n=1) 2=9% (n=1)
Question 11 FALSE	The decision to begin palliative care is when everyday care becomes hard for families. DELETED	FOR DELETION I think this question can be deleted as not relevant. While the concept that increasing care needs are the basis of commencing a palliative approach is wrong, this fact may indicate that a person is increasingly frail, deteriorating, advancing in their dementia, etc, so is ambiguous.	1. Swap care to approach 2. Not sure what the aim of this question is and again for a care worker may be hard to conceptualise what you mean	4=81% (n=9) 3= 9% (n=1) 2= 9% (n=1)	4=72% (n=8) 3=9% (n=1) 2=9% (n=1) 1=9% (n=1)
Question 12 TRUE	Quality palliative care is individualised and respects the person's preferences and wishes.	Providing a palliative approach is based on the individual's needs and wishes.	1. Explain individualised 2. ? Providing a PA is	91% (n=11) 4=83% (n=9) 3=9% (n=1) 2=9% (n=1)	4=100% (n=11)
Question 13 TRUE	Families can experience grief before the death of their family member.	Families can often experience grief before the death of their family member.	Can often experience	4=100% (n=11)	4=91% (n=10) 3=9% (n=1)
Question 14	Families cope better	Families need to understand	1. I agree that family members should	4=100%	4=100%

TRUE	when they understand what is happening and are involved in decision-making.	what is happening and be involved in decision-making.	be aware, understand what is happening to their family member and be involved in all decision-making. However not so sure that ' all' family members ' cope better' with this extent of knowledge.	(n=11)	(n=11)
Question 15 FALSE	Effective communication is based on listening and talking. DELETED	There are many elements to effective communication, so the answer was False. I think it is relevant for NAs because communication skills/strategies they can use: eye/body language, empathy etc. are important, not just information giving. Would like to keep this question as is	1. There are many elements to effective communication. Listening and talking are two primary elements. 2. what about observing and using empathy? not sure—empathetic listening might be clearer 3. Also by watching persons actions which sometimes can show they are in pain	4=72% (n=8) 3=9% (n=1) 2=18% (n=2)	4=63% (n=7) 3=18% (n=2) 2=18% (n=2)
Question 16 TRUE	The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube is because he/she can no longer swallow safely.	The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.	Explain what a ' PEG' is.	4=100% (n=11)	4=91% (n=10) 3=9% (n=1)
Question 17 TRUE	When a person with dementia is admitted to a residential aged	When a person with dementia is admitted to a residential aged care facility it is usually because	1. Most people with dementia (only) present to the facility due to behavioural difficulties that the family	4=63% (n=7) 3=18%	4=63% (n=7) 3=27%

	care facility it is because they have developed advanced symptoms of the disease. DELETED	they have developed advanced symptoms of the dementia that affect their care.	could no longer control. I found this to be mainly in the moderate dementia stage when people are still mobile. Again many people presented to the RACF with mild dementia and mobility issues. 2. Is dementia the 'disease', or are you referring to a terminal illness comorbid with the dementia? 3. many stages of dementia, admission time varies with the individual 4. usually	(n=2) 2=18% (n=2)	(n=3) 2=9% (n=1)
Question 18 FALSE	To prevent a person with dementia from dying it is important to encourage feeding. DELETED	Encouraging feeding in a person with dementia will prevent them from dying.	1. People with dementia do forget to eat so it is important to encourage them to eat. However if their gag reflex is gone you may be encouraging pneumonia or choking. It is also important to keep people with dementia from wandering away (i.e. off roads), away from sharp implements (scissors) and limit falls (trip hazards) to help keep them alive. 2. Are they not eating because of the dementia or because of a comorbid terminal illness? If dementia is their only condition then reminding/encouraging them to eat is	4=63% (n=7) 3=9% (n=1) 2=18% (n=2) 1=9% (n=1)	4= 63% (n=7) 3=18% (n=2) 2=18% (n=2)

			important. However, if they are dying, it might not be appropriate, depending on their condition. 3. Confusing 4. ambiguous it is important to encourage feeding in any one so this is a bit confusing—'Encouraging feeding in a person with dementia will prevent them dying' is maybe clearer		
Question 19 TRUE	In a palliative approach a person can be offered food for comfort against medical advice if the family understands the risks of feeding. DELETED	In a palliative approach a person can be offered food for comfort against medical advice if the person wants to eat and the risks of feeding have been explained to the person and their family.	1. Patient's opinion should be the most important. I am assuming they are conscious because you wouldn't be talking about feeding them otherwise. So, if they are conscious, their wishes should be paramount, regardless of what the family wants.	4= 81% (n=9) 3=9% (n=1) 2=9% (n=1)	4=91% (n=10) 2=9% (n=1)
Question 20 FALSE	The needs of people requiring palliative care are the same.	The needs of people requiring a palliative approach are the same.	1. The needs of people requiring palliative care are the same for everybody. 2. Change palliative care to approach	4=81% (n=9) 3=18% (n=2)	4=91% (n=10) 3=9% (n=1)
Question 21 FALSE	Hospital is the best place for a dying person because the problem can be identified and	No Comments.		4=100% (n=11)	4=100% (n=11)

	treated. DELETED CV(2)				
Question 22 FALSE	Not everyone involved in the care of a person with a life-limiting illness needs to be able to discuss dying and death. DELETED	Not everyone involved in the care of a person receiving a palliative approach needs to be able to discuss dying and death.	1. They need a clear understanding of the process 2. I'm not sure about this as sometimes there are carers who deliver great care but cannot discuss death—the important thing is that they refer any questions to someone who can discuss it—on the other hand if you can't discuss death and dying should you be working in this area—I don't know	91% (n=11) 4=9 3=1 2=1	91% (n=11) 4=8 3=2 2=1
Question 23 TRUE	When a person can no longer do anything on their own, it is a sign that they are approaching the end stage of their illness.	When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.	1. People with spinal injury? 2. MND, MS, Huntington's [disease], Dementia, all have long trajectories post disability so if that is the answer your looking for OK if not may need revising	100% (n=11) 4=9 3=2	100% (n=11) 4=9 3=2
Question 24 FALSE	The age group of people with palliative care needs is getting younger. DELETED FACE VALIDATION	FOR DELETION. Experts were ambivalent about this question when they completed the Knowledge Questions. I included it because it is in the data but may not be relevant or easily supported. I think it should be deleted regardless of CVI.	1. Change palliative care to palliative approach...The age group of people requiring a palliative approach....	100% (n=11) 4=9 3=2	100% (n=11) 4=10 3=1

Question 25 TRUE	Explaining the purpose of your care maintains a person's dignity even when they are not responding.	Explaining what care you are going to provide maintains a person's dignity even when the person is not responding.	1. 'care' unclear....do you mean physical care?	100% (n=11) 4=10 3=1	100% (n=11) 4=10 3=1
Question 26 FALSE	Frequent repositioning is always necessary to prevent pressure sores when a person is receiving palliative care.	Frequently changing a person's position to prevent pressure sores is always necessary when a person is receiving a palliative approach.	1. Some might not understand what repositioning is 2. in the last stages only if required for comfort 3. repositioning is also for comfort, other factors determine frequency of position change i.e. type of mattress 4. depends if you are using a pressure relieving mattress or chair then repositioning is not needed as often—also depends on skin integrity and assessing this—not sure what you want as response	100% (n=11) 4=7 3=4	100% (n=11) 4=8 3=3
Question 27 TRUE	Identifying symptoms is the first step in being able to manage symptoms.	Identifying symptoms (physical signs) is the first step in being able to manage symptoms.	1. What is a 'Symptom'	91% (n=11) 4=10 2=1	100% (n=11) 4=10 3=1
Question 28 TRUE	Families or carers who know the person best are usually the		No Comment.	100% (n=11)	100% (n=11)

	first to detect changes in a person's condition.			4=11	4=11
Question 29 FALSE	Advance Care Plans can be completed when the person's disease is known. DELETED	Advance Care Plans can only be completed when a person's illness (or disease) is known.	1. I'm unsure. Can an ACP be completed prior to the person knowing the exact disease, which will be responsible for their demise? 2. Some may not know what Advance Care Plans are. 3. Bit confusing as it stands. ACP can be completed when the person's disease is know; they can be completed before as well. 4. Can be completed at any stage while person is capable even if free of disease 5. What about: ADP can only be completed when a person's illness (or disease) is known. 6. Not sure what is being asked here. Is it that we have to wait until a person's disease is known before completing an ACP? (Answer: false). Bit confusing as it stands. ACP can be completed when the person's disease is know; they can be completed before as well. 7. not sure as you can start and ACP once disease is known however, needs	91% (n=11) 4=6 3=4 2=1	91% (n=11) 4=8 3=2 2=1

			lots of revisiting—currently an issue as many just get done and filed in RACF without review.		
Question 30 TRUE	Observing a person for pain provides more accurate information than pain assessment tools. DELETED	Observing a person for pain is as important as pain assessment tools. (I have amended question as I think it is important: NAs do need to know this.)	1. This is a little confusing as many pain tools are based on observation. 2. assessment too???? explain. 3. Difficult question to answer. 'pain assessment tools' is very broad. Maybe something like: 'observing a person for pain is an important part of pain assessment and can be as or more informative than pain assessment tools'. Part of pain assessment is observing person 4. pain assessment tools necessary 5. I think this would be better if it stated observing a person for pain is as important as pain assessment tools	82% (n=11) 4=6 3=3 1=2	91% (n=11) 4=6 3=4 1=1
Question 31 TRUE	Pain relief before providing physical care helps a person experiencing pain feel more comfortable during care routines.	Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.	1. better to give an example for more clarity e.g. giving pain relief before wound dressing. 2. I understand this is a quantitative questionnaire, but I would prefer: 'Pain relief before providing physical care can help a person experiencing pain feel more comfortable during care routines'.	100% (n=11) 4=9 3=2	100% (n=11) 4=10 3=1

Question 32 FALSE	Pain relief should only be given for pain that is present. DELETED	Pain relief should only be given when people have pain.	1. Not sure about this question. My first thought was, are you trying to determine whether it is alright to give pain relief to advance death? Maybe a question about the importance of accurate and comprehensive pain assessment before treating pain to ensure that treatment is appropriate. 2. Are you trying to evaluate different aspects of suffering or simply physical pain? If physical pain—what about simplifying statement to: Pain relief should only be given for people who have pain.	91% (n=11) 4=9 3=1 2=1	91% (n=11) 4=10 2=1
Question 33 TRUE	If a person has pain it is best to leave repositioning them unless necessary. DELETED	If a person has pain it is best to leave repositioning until after pain relief has been given.	1. Be sure that the repositioning is not forgotten though. Give breakthrough medication and come back in 20 minutes. 2. Not very clear. Restructure the sentence. 3. Depends on cause of pain 4. position change may relieve pain 5. again if they are on a pressure relieving device this may be true but if not the word necessary is ambiguous—who determines what necessary is when you are not trained?	91% (n=11) 4=8 3=2 2=1	91% (n=11) 4=9 3=1 2=1

Question 34 TRUE	Pain can be caused by physical, psychological, social or spiritual distress.	Question to remain as is.	1. A little confusing as the other influences can impact on the person's experience of pain.	100% (n=11) 4=9 3=2	100% (n=11) 4=10 3=1
Question 35 TRUE	Facial expressions, calling out and resisting care can be the result of pain.	Facial expressions, calling out and resisting your care can be the result of pain.	1. 'resisting care' have to be explained	100% (n=11) 4=10 3=1	100% (n=11) 4=11
Question 36 FALSE	When a person is receiving pain relief, they no longer experience pain.	When a person is receiving pain relief, they no longer feel pain.	1. This is a difficult question as pain is whatever the individual says it is with or without pain relief, and as many people in the palliative situation are unable to verbalise then 'no pain' is an assumption that can not be made. 2. The word 'experience pain' can be replaced by 'feel pain'.	100% (n=11) 4=9 3=2	100% (n=11) 4=10 3=1
Question 37 TRUE	A dry mouth is one of the most common symptoms in a person with palliative care needs.	A dry mouth is one of the most common symptoms in a person who is no longer eating or drinking.	1. A bit open ended. As some people in their palliative journey are well hydrated, in the later stages nearer death this statement may be true. 2. It is the medication that usually causes dry mouth and can occur in anyone	100% (n=11) 4=9 3=2	100% (n=11) 4=9 3=2

Question 38 FALSE	A family conference aims to inform the family what care the person will receive. DELETED	Question to remain as is.	1. One of the aims of a family conference is to inform the family what care their family member will receive their may also be options to care presented at a family conference. A family conference is a discussion which allows the family to be given information to gain an understanding of their relatives health condition and what is being done and what can be done in the future to care for their relative. It is also a opportunity for the family to ask questions, give preferences to the care their relative will receive (mum likes to sit by the window in the afternoon, can she bath in the morning instead) so that care is tailored to the individual resident and family. 2. it does do this but more importantly it aims to involve the family in discussing care and treatment and to involve them in deciding what care a person receives -so i think the question is limiting	91% (n=11) 4=10 2=1	91% (n=11) 4=9 3=1 2=1
Question 39 TRUE	A team approach in palliative care is important because individuals and their families need a broad	Working as a team when providing a palliative approach is important because individuals and their families may experience a broad range of	1. team approach = working as team 2. A team approach when providing a palliative approach is important because individuals and their families	100% (n=11) 4=10	100% (n=11) 4=11

	range of skills.	issues.	may experience a broad range of issues.	3=1	
Question 40 FALSE	A person's wish to die means that the person will die soon.	A person expressing a wish to die means that the person will die soon.	1. A person expressing a wish to die means that the person will die soon. 2. I have known people who have willed themselves to die but failed for years	100% (n=11) 4=9 3=2	100% (n=11) 4=9 3=2
Question 41 TRUE	The early phase of dying can begin up to three weeks before a person dies. DELETED	A person can begin to approach the end of life weeks before death. (Early identification (of dying) is discussed throughout the literature as important and I think the statement should be included with amendment.)	1. What is 'early phase of dying'??? 2. Is it really that easy to identify? 3. it can begin 10–12 weeks earlier and fluctuate in complex chronic disease so is very unsettling to staff and family members—I think putting a time on it is risky as it is so variable	72% (n==1) 4=8 2=2 1=1	82% (n=11) 4=9 2=1 1=1
Question 42 TRUE	Signs of active dying can be present hours to days before death occurs.	Signs that death is near can be present hours to days before death occurs.	1. I hope you clarify what ' active dying'; in the previous Q. What are the signs of 'active dying';????	91% (n=11) 4=10 2=1	100% (n=11) 4=11
Question 43 FALSE	Changes in breathing are not a normal part of the dying process. DELETED	Changes in breathing always indicate that death is near.	1. Sometimes they might be; other times, not. Tends to depend on what the patient is dying from. Could you ask something like: 'Changes in breathing always indicate that death is imminent' (answer: false).	91% (n=11) 4=9 3=1	91% (n=11) 4=10 2=1

				2=1	
Question 44 TRUE	Grief and loss is the last stage after a person has died. DELETED	Bereavement (dealing with loss) is part of a palliative approach.	1. Last stage of what? 2. last stage? Last stage of a palliative approach?	91% (n=11) 4=9 3=1 1=1	91% (n=11) 4=10 1=1
Question 45 FALSE	If you know a person's cultural background it is easy to provide culturally sensitive palliative care. DELETED CV(2)	Question to remain as is.	1. it is 'easier' 2. I think it would be better worded easier' not ' easy' 3. ' culturally sensitive palliative care'; can you simplify. 4. 'If you know a person's cultural background, it is easier to provide culturally sensitive care' . Even if we know a person's a cultural background, it will not always be ' easy to provide culturally sensitive care' because there might be other obstacles or our knowledge may not be sufficiently extensive. 5. replace easy with easier? 6. hope this is what you mean as its never easy and everyone is unique what suits a person from one culture often doesn't suit another so this question	100% (n=11) 4=5 3=6	100% (n=11) 4=7 3=4

			could be ambiguous		
Question 46 FALSE	It is better to provide information about palliative care to people from culturally and linguistically diverse backgrounds in English.	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.	1. Should be in their own language so they understand 2. interpreter services and family may assist in communication	100% (n=11) 4=11	100% (n=11) 4=11
Question 47 FALSE	Assisting an older person to socialise with others will prevent them from feeling lonely or depressed. DELETED	Encouraging an older person to socialise will stop them from feeling lonely or depressed.	1. As long as they are wiling to socialise. Will prevent? can prevent? 2. Difficult question to answer. Usually, this would be true, but it rather depends on the individual and their condition. Maybe: 3. Assisting an older person to socialise with others will prevent them from feeling lonely or depressed. 4. in most cases 5. it MAY help them but it might not so unsure of what you mean in this one	100% (n=11) 4=9 3=2	91% (n=11) 4=9 3=1 2=1
Question 48 TRUE	Truthful and respectful communication improves psychological well	Respectful communication can improve how a person feels.	1. However this may not always be the case with someone with dementia to be 100%truthful, but always improves with being respectful. 2. 'psychological well being': Simplify	100% (n=11) 4=8 3=3	100% (n=11) 4=9 3=2

	being.		3. again CAN improve is better than a definitive statement		
Question 49 TRUE	Spiritual care involves asking a person about the things that are important to them.	Spiritual care identifies what is important to a person.	1. please restructure for more clarity.	100% (n=11) 4=10 3=1	100% (n=11) 4=11
Question 50 TRUE	Professional development in palliative care encourages self-reflection. MOVED TO SKILLS	A palliative approach requires developing the skill of self-reflection.	1. Too sophisticated words: 'Professional development 'and 'encourages self-reflection'. Simplify.	91% (n=11) 4=9 3=1 2=1	100% (n=11) 4=10 3=1
Question 51 FALSE	Providers of palliative care do not need professional development if they are able to learn on the job. MOVED TO ATTITUDES	In a palliative approach professional development is not necessary when care providers can learn on the job.	1. Education is always empowering to any one, however this can be done also in informal ways, for example with family members who wish to be part of providing the care. 2. If they already know what 'professional development' is.	100% (n=11) 4=9 3=2	100% (n=11) 4=10 3=1
Comments on design and format		Easy to understand Easy to use Satisfactory			

		Was good	
		It did take about an hour as I added a few comments	
		The design was user friendly	
		Some needed restructuring	
		Easy to follow	
		Good, no problems	
		Very easy to navigate and understand	
		Good design and easy format to follow	
Please rate whether you thought the items achieved a difficulty grading of one third easy, one third moderately difficult and one third difficult	Yes, difficulty grading achieved	(n=7) 67%	Some ambiguous questions that for a care worker may be confusing
	Not quite, needed easier questions	(n=1) 9%	I have already given my opinion to individual questions. Overall, I think most questions are relevant. But needs to be simplified. We have lot of CALD staff who may not understand 'difficult' words.
	Not quite, needed more moderately difficult questions	(n=1) 9%	
	Not quite, needed more difficult questions	(n=2) 18%	I think that aiming at the AIN level of employee most of the questions were at a good level.

Results of Content Validation of Skills Questionnaire by experts (n=9)

Original Statement	**Revised items**	**Expert comments**	CVI Clarity (rated either 3 or 4)	CVI Relevance (rated either 3 or 4)
Inst**ructions for completing the questionnaire** The purpose of these questions is to learn about your skills when providing care with a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. • Please mark the statement that corresponds best to what you do. • Please respond to ALL statements.	The purpose of these questions is to learn about your skills when providing a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. • Please mark the statement that corresponds best to what you do. • Please respond to ALL statements.	When providing a palliative approach	4=78% (n=7) 3=22% (n=2)	-
1. I observe what an individual can do independently.	Question to remain as is	Will this depend on what the observation is and the level of the worker	4=89% (n=8) 2=11% (n=1)	4=89% (n=8) 3=11 (n=1)
2. I provide care according to an individual's care plan.	Question to remain as is	I assume that they understand what a care plan is.	4=100% (n=9)	4=100% (n=9)
3. I update individual care plans based on observation of the	I contribute to the updating of individual care plans based on my	1. Pass on information as on	4=89% (n=9)	4= 100%

	individual.	observation of the individual.	night shift. 2. Again will depend on role in the organisation and if they have this delegation 3. I tell RN and she updates care plan where I work 4. The question is relevant. But can AINs update care plans? In RACFs RNs update care plans with consultations with AINs.	3=11% (n=1)	(n=9)
4.	I provide care in line with Advance Care Directives.	DELETE	1. When you say advance care directives do you mean the statue documents or do you mean advance care plans. Again on a day to day basis how much does this direct care and at what level would this decision be made 5. RN does 6. RN will manage this at my work and let us know 7. Important to know peoples wishes in case something happens we know what to do. 8. RN directs care in line with end of life wishes	4=88.88% (n=7) 3=11% (n=1) 2=11% (n=1)	4=67% (n=6) 3=22% (n=2) 1=11% (n=1)
	5. I provide individualised	Question to remain as is	1. I do to my ability, tell RN if needs more	4=100% (n=9)	4=100% (n=9)

	personal care.		9. I assume they know what an individualised means. Current TAFE courses introduce these term. So new staff will be familiar with the terms.		
6.	I observe an individual's ability to feed themselves.	DELETE	These are very generic statements that are not necessarily specific to palliative care	4= 100% (n=9)	4= 89% (n=8) 1=11% (n=1)
7.	I safely feed an individual.	DELETE	What do you mean by feeding safely?	4=89% (n=8) 3=11% (n=1)	4=88% (n=8) 1=11% (n=1)
8.	I encourage fluids on a regular basis.	DELETE	1. In the palliative phase of end stage care I think the goal of what you are trying to achieve, that is if offering regular fluids is going to enhance someone's well being, then offer regularly, but if it serves to aggravate them, the goal needs to be considered. 2. I offer a drink on each round if person awake 3. Only as long as person can swallow, but always keep mouth moist with mouth care	4=100% (n=9)	4=88% (n=8) 1=11% (n=1)
9.	I provide mouth care based on my observation of individual need.	I provide mouth care based on evidence-based assessment.	Should be based on an evidence based assessment	4=89% (n=8) 2=11% (n=1)	4=100% (n=9)

	DELETED CV(2)				
10.	I observe for problems with an individual's skin.	I observe for problems with an individual's skin, such as a pressure area.	Maybe give examples of skin problems	4=89% (n=8) 3=11% (n=1)	4=100% (n=9)
11.	I provide comfort that an individual needs.	I provide both physical and emotional comfort, depending on individual need.	1. A bit broad how would different people interpret this 2. Give examples of comfort	4=78% (n=7) 3=11% (n=1) 2=11% (n=1)	4=100% (n=9)
12.	I position people for comfort.	Question to remain as is	–	4=100% (n=8) 2=11% (n=1)	4=100% (n=9)
13.	I observe for pain when I provide care.	I observe for pain using a valid and reliable pain assessment tool.	Should be I use a valid and reliable pain assessment tool	4=89% (n=8) 2=11% (n=1)	4=100% (n=9)
14.	I ask an individual whether she/he has pain.		I am comfortable asking, but do not always ask every time I provide care	4=89% (n=8) 3=11% (n=1)	4=100% (n=9)
15.	I record pain using a pain assessment tool, such as the Abbey Pain Scale, in line with care plan directives	DELETE	1. I assess someone's pain, but do not always use an pain scale formally to do so, although will use facial expression etc to assess 2. I report when I think someone has pain to my RN. I do not know what it is, but I know when someone looks	4=56% (n=6) 2=33% (n=2) 1=11% (n=1)	4=78% (n=7) 1=22% (n=2)

		uncomfortable or may have pain 3. The abbey is only for people with dementia so i would add visual analogue scale or for people unable to communicate an abbey pain scale 4. I will tell RN and they will investigate, and act. 5. Not everybody will know about Abbey Pain Scale 6. I know my residents and can tell when a change like more pain could be happening, even if they can't tell me in words their actions		
16. I report pain to the registered nurse or person in charge.		As the registered nurse I would be reporting the pain experienced by the resident to myself. I would document and make referrals as necessary.	4=100% (n=9)	4=89 % (n=9) 3=11% (n=1)
17. I provide non-medication strategies, such as gentle massage, in order to manage pain.		We would like to do more massage etc but funding restraints can limit ability to provide this type of care.	4=100% (n=9)	4=100 % (n=9)
18. I evaluate the effectiveness of pain management strategies.	I evaluate the effectiveness of pain management strategies using a validated pain assessment tool.	Say how to evaluate (examples)	4=89%% (n=8) 3=11% (n=1)	4=100 % (n=9)

19. I monitor and report bladder or bowel problems.	I monitor for bladder or bowel problems, document and report as necessary.	Give examples.	4=89% (n=8) 3=11% (n=10	4=100 % (n=9)
20. I monitor and report increasing confusion.	I monitor and report new or increasing confusion.	Would it be any confusion or just increasing. The short form CAM is a good evidence-based tool.	4=89% (n=8) 2=11% (n=1)	4=100 % (n=9)
21. I monitor and report problems with breathing	I monitor and report problems or changes in an individual's breathing.	Give examples.	4=89 % (n=1) 3=11% (n=1)	4=100 % (n=9)
22. I monitor and report any changes in an individual's condition	I monitor and report any physical, emotional or behavioural changes.	Are you referring here to physical changes or any changes i.e. emotional?	4=89% (n=8) 2=11% (n=1)	4=100 % (n=9)
23. I support families by addressing their concerns	I support families by addressing their concerns, or report these to a more senior person.	1. Often families will stay at night if loved one low or dying, I do whatever I can for them 2. or reporting the concerns to a more senior person	4=78%% (n=7) 3=11% (n=1) 2=11% (n=1)	4=100 % (n=9)
24. I communicate with families by providing information	I communicate with families by providing information appropriate to my level of understanding.	1. If not sure I will get RN 2. appropriate to my level and understanding 3. To where I feel comfortable, but usually I will get RN for families	4=78%% (n=7) 3=11% (n=1) 2=11% (n=1)	4=89 % (n=8) 3=11% (n=1)
25. I support families when they are grieving	I support families when they are grieving by showing care and understanding.	1. again under supervision 2. showing care and respect for residents shows family we care	4=78%% (n=7) 3=11% (n=1)	4=100 % (n=9)

		3. say how to support	2=11% (n=1)	
26. I direct families to other members of the care team when they need further advice	Question to remain as is	–	4=100 % (n=9)	4=100 % (n=9)
27. I report the needs of individuals to the registered nurse or person in charge.	Question to remain as is.	I document, make appropriate changes or referrals, and pass on the information to the registered nurse on the next shift for continuity of care	4=100 % (n=9)	4=89 % (n=8) 3=11% (n=1)
28. I raise the concerns of (advocate for) the individuals in my care.	Question to remain as is	May not know the term advocate (if they have not done a course recently)	4=89% % (n=8) 3=11% (n=1)	4=100 % (n=9)
29. I contribute at team meetings or family conferences.	DELETE	I will pass on concerns to other shifts but don't do these at night RN will always ask for my input	4=78% (n=7) 3=22% (n=2)	4=67%% (n=6) 3=11% (n=1) 2=22% (n=2)
30. I communicate with doctors about the needs of an individual, as necessary.	DELETE	1. Not my role 2. if appropriate or if directed by the senior nurse 3. RN job 4. In RACFs AINs do not directly communicate with Drs.	4=89% (n=8) 2=11% (n=1)	4=56% (n=5) 2=22%(n=2) 1=22% (n=2)
31. I communicate with other allied health providers about the needs of an	DELETE	1. Again will pass on 2. again where appropriate and under direction	89% (n=9)	68% (n=9)

	individual, as necessary.		3. I will talk to them but RN does this and initiates 4. Who are allied health (give examples) 5. RN will do		
32.	I contribute to problem solving to seek solutions.	Question to remain as is	happy to offer suggestion	4=89 % (n=8) 3=11% n=1	4=100 % (n=9)
33.	I support team members	I support team members to the best of my ability.	To my ability	4=89 % (n=8) 3=11% n=1	4=89 % (n=8) 3=11% n=1
34.	I recognise the signs when an individual is approaching the end of life	I recognise the signs when an individual is in the last days or hours of life.	I would be much more specific, in the last days or hours of life. people interpret approaching end of life in different ways	4=89% (n=8) 2=11% n=1	4=100% (n=9)
35.	I provide privacy for a dying person and his/her family	Question to remain as is		4=100 % (n=9)	4=100 % (n=9)
36.	I am attentive to a dying individual's care	Question to remain as is		4=89% (n=8) 2=11% n=1	4=100 % (n=9)
37.	I maintain the dignity of a dying individual	I demonstrate care and respect right to the end of a person's life.	dignity is a word often said but do people understand at this level what it is (also cultural issues)	4=89% (n=8) 2=11% n=1	4=100 % (n=9)
38.	I manage my own emotional responses when	I find ways to cope with my own emotional responses when a	1. What if you can't, perhaps I am aware of where to seek help in	67% (n=6)	4=100 % (n=9)

	a person I have been caring for has died	person I have been caring for has died.	2.	managing my emotional responses How to manage?	3=11% n=1 2=11% n=1 1=11% n=1	
39.	I maintain an individual's safety.	Question to remain as is		–	4=100 % (n=9)	4=100 % (n=9)
40.	I demonstrate understanding in the care I provide.	Question to remain as is		–	4=100 % (n=9)	4=100 % (n=9)
41.	I build a relationship with the people I care for.	Question to remain as is		–	4=100 % (n=9)	4=100 % (n=9)
42.	I actively listen to the people I care for.	I listen attentively to the people I care for.		do people know what active listening is	4=89% (n=) 2=11% n=1	4=100 % (n=9)
43.	I am able to care for a person with difficult behaviours.	I am able to care for a person with challenging behaviours.		difficult behaviours is a very negative label	4=78% (n=7) 3=11% n=1 2=11% n=1	4=100 % (n=9)
44.	I reflect on my performance and attitudes when providing a palliative approach.	I reflect on what I say and do when providing a palliative approach.		May not understand	4=89% (n=8) 2=11% n=1	4=100 % (n=9)
45.	When I am unsure about how to do something, I seek advice.	Question to remain as is		–	4=100 % (n=9)	4=100 % (n=9)

46. I find ways to manage stressful situations with individuals and families.	DELETE	1. or i know how to get support to do this 2. Every day 3. Give examples	4=67% (n=6) 3=11% n=1 2=22% n=2	4=89% (n=8) 2=11% n=1
47. I am able to maintain a worklife balance for my own wellbeing.	I am able to maintain a work-life balance for my own wellbeing.	Hard sometimes	4=89 % (n=8) 3=11% n=1	4=89 % (n=8) 3=11% n=1
48. I learn how to provide a palliative approach by doing.	I learn how to provide a palliative approach by supporting individuals in my care.	1. Have worked in high care a long time 2. Not sure that palliative care is about 'doing'- should it not be about 'being'? Traditionally AINs are focused on tasks which is about 'doing' rather than supportive care which is 'being' 3. doing what?	4=78 % (n=7) 3=22% n=2	4=100 % (n=9)
Are there any other skills that you think nursing assistants use when providing a palliative approach?	Supporting each other What about communication skills. How to respond to families?		Item 31 Items 23,24,25,26	
Is the design and format of this questionnaire user friendly	Yes = 88% n=8 No = 11% n=1	I see why you force people to use the same descriptors but some questions suit this better than others		

Results of Content Validation of Attitudes Questionnaire by experts (n=12)

Original Statement	Expert comments	Revised items	CVI Clarity 4 = very clear 3 = minor revision 2= major revision	CVI Relevance 4 = very relevant 3 = minor revision 2= major revision
Instructions for completing the questionnaire The purpose of these statements is to learn how nursing assistants feel providing a palliative approach. All statements concern the care of an individual with palliative care needs and his/her family in the place where you provide care. • Please indicate how much you agree or disagree with each of the following statements. • Please respond to ALL statements.	1. Maybe shorten the second sentence.	The purpose of these statements is to learn how nursing assistants feel providing a palliative approach. All statements concern the care of an individual **receiving a palliative approach** and his/her family in the place where you provide care. **Instructions for completing the questionnaire** • Please indicate how much you agree or disagree with each of the following statements. • Please respond to ALL statements.	4= 92% (n=11) 3=8% (n=1)	-
1. A palliative approach can help improve a person's quality of life.	1. As long as they know what QoL is.	A PALLIATIVE APPROACH CAN HELP A PERSON'S QUALITY OF LIFE.	4=92% (n=11) 3=8.3% (n=1)	4=92% (n=11) 3=8.3% (n=1)

1.	In a palliative approach, people are best cared for in bed.	1. Palliative people are best cared for in whatever they wish and are comfortable in. 2. Excellent question as it is value based and will bring out an attitude that needs challenging		4=83.3% (n=9) 3=17% (n=2)	4=75% (n=8) 3=25% (n=3)
2.	I am unable to improve a person's quality of life with a palliative approach. DELETE	Hate double negatives so would prefer I am able to improve the quality of life with a pA		4=83.3% (n=10) 3=8.3% (n=1) 2=8.3% (n=1)	4=8.3% (n=9) 3=8.3% (n=1) 1=83.3% (n=1)
3.	I am able to provide comfort when a person is dying. 3	1. I think that to say on most occasions I am able to provide comfort is better as there will be times when comfort is unable to be addressed. Also what is 'comfort'—bit nebulous and may be based in values too? 2. I think it is relevant because it's about empowering but I'm not sure if comfort means the same to everyone?	I help improve the quality of care when a person is dying.	4=83.3% (n=10) 3=16.6% (n=2)	4=83.3% (n=10) 3=16.6% (n=2)
4.	Spending time with a person who is approaching the end of life is important. 4	1. Hard to do with time allowed with staffing 2. Hard question though as for		4=100% (n=12)	4=100% (n=12)

		many aged care workers time is limited and their frustration is high when they can't spend time with a person			
5.	Identifying a person's emotional, social and spiritual needs is my responsibility.5	1. You might say: being aware of a person's etc 2. As long as they know the meaning of the term emotional, social and spiritual 3. Its not only their responsibility 4. RN will do that 5. 'I play a strong role in identifying a person's emotional, social and spiritual needs' may be better as I feel they are not responsible but are partially so? or ' I see myself as an important part of the team in identifying …'	Being aware of a person's emotional, social and spiritual needs is my responsibility.	4 = 66% (n=8) 3=25% (n=3) 2=8.3% (n=1)	4=100% (n=12)
6.	Explaining the purpose of my care demonstrates respect even when an individual is unable to respond.6			4=92% (n=10) 3=8% (n=1)	4=100% (n=12)
7.	Easing suffering is usually not possible in a palliative approach. DELETE	1. again I hate double negatives—too confusing to the brain and triggers a negative pathway rather than a proactive, empowering thought		4=83% (n=10) 3=8% (n=1)	4=83% (n=10) 3=8% (n=1) 1=8% (n=1)

		process.		2=8% (n=1)	
8.	I find it difficult to care for people who are suffering. DELETE	I answered for me but i think this would be a good question for care workers		4=83% (n=10) 3=17% (n=2)	4=83% (n=10) 3=8% (n=1) 1=8% (n=1)
9.	Providing a palliative approach is not the same as usual care DELETE.	1. May be a little ambiguous because although a PA is the way we should all do care all the time really for older people—there are some subtle differences where focus may be different like diet, eating and drinking, fluid intake, movement—care timing etc. 2. Not sure what you mean	Unable to clarify	4=92% (n=11) 3=8% (n=1)	4=83% (n=10) 3=17% (n=2)
10.	Hospital is the best place for a dying person because their problems can be identified and treated. DELETE	1. Sometimes families think hospital is better		4=75% (n=9) 3=17% (n=2) 2=8%(n=1)	4=83.3% (n=10) 3=8.3% (n=1) 1=8.3% (n=1)
11.	Individuals receiving a palliative approach are unable to do anything on their own. DELETE	-		4=92% (n=11) 3=9% (n=1)	4=83% (n=10) 3=9% (n=1) 2=9% (n=1)
12.	I feel sad caring for people approaching the end of their	1. Sometimes I feel sad I think that is normal, however always		4=100% (n=12)	4=92% (n=11)

	life. DELETE	professional and compassionate. 2. Ok to feel sad but need to differentiate between sad and deeper emotion while caring for person and remaining sad in person time			2=8% (n=1)
13.	Caring for a person with a palliative approach is rewarding.7	-		4=92% (n=11) 3=8% (n=1)	4=83% (n=10) 3=17% (n=2)
14.	I provide more than physical care when providing a palliative approach. DELETE	1. What is physical care? 10. Not sure what this question is about as I can't see relevance and could confuse person?		4= 67% (n=8) 3=25% (n=3) 2=8% (n=1)	4=75% (n=9) 3=17% (n=2) 2=8% (n=1)
15.	Providing a palliative approach based on an individual's wishes improves their quality of life.8	Maybe: Providing a palliative approach based on an individual's wishes usually (or can) improves their quality of life.	Providing a palliative approach based on an individual's wishes can improve quality of life.	4= 75% (n=9) 3=25% (n=3)	4=92% (n=11) 3=8% (n=1)
16.	In a palliative approach, families need my support.9	-		4=92% (n=11) 3=8% (n=1)	4=92% (n=10) 3=8% (n=1)
17.	I prefer to ask other team members to talk to families about difficult issues.	I answered for me but I think any answer would be ok —I like this question as it has no right or wrong but allows care worker to reflect on		4= 83% (n=10) 3=17%	4= 75% (n=9) 3=17% (n=2)

DELETE	their own capacity in this area.	(n=2)	1=8 (n=1)
18. I find it hard to control my emotions when families are grieving. 10	It depends on the situation, how long I have known them.	4=92% (n=11) 3=8% (n=1)	4=92% (n=10) 3=8% (n=1)
19. It is best to give minimal care to a dying person. DELETE	1. Difficult because sometimes it is better to give minimal care especially if a person has symptoms triggered by intervention however, usually care intervention increases even though this may not be a best interest just because the person is dying. 2. It is relevant if backed by discussion - but as it is an 'IT DEPENDS' question I think it is a hard one.	4=83% (n=10) 3=8.3% (n=1) 2=8.3% (n=1)	4=67% (n=8) 3=8.3% (n=1) 2=8.3% (n=1) 1=16.7% (n=2)
20. I am not comfortable caring for a dying person. DELETE	Direct and short question—I like it.	4=92% (n=11) 3=8% (n=1)	4=83.3% (n=10) 3=8.3% (n=1) 1=8.3% (n=1)
21. I am not comfortable with care of the body when a person has died. DELETE	It is the last nice thing I can do for them	4=92% (n=11) 3=8% (n=1)	4=83.3% (n=10) 3=8.3% (n=1) 1=8.3% (n=1)

22.	Families should leave care to those paid to provide care. DELETE	-		4= 83% (n=10) 3=17% (n=2)	4= 67% (n=8) 3=17% (n=2) 1=17% (n=2)
23.	Understanding what a person is going through as they approach the end of life helps me provide a palliative approach.11	1. We are aware of physical and emotional stages of dying, however do we ever really know or understand what the person is going through?	Understanding physical and emotional changes at the end of life helps me provide a palliative approach.	4=92% (n=11) 3=8% (n=1)	4=92% (n=11) 3=8% (n=1)
24.	A caring and compassionate attitude are essential in a palliative approach.12	1. What is compassionate? Maybe: 'A caring and compassionate attitude are essential in providing a quality palliative approach.' I suspect that palliative care can be provided without care and compassion, but its quality and effectiveness would be questionable.	A caring attitude improves the quality of a palliative approach.	4= 83% (n=10) 3=17% (n=2)	4=100% (n=12)
25.	In a palliative approach, I help a person feel at home. DELETE	1. Not sure I agree with the way this statement reads. I understand that RACFs are considered the person's 'home', although some residents might disagree. I think this would read better by changing to: ' When providing a palliative approach I help the person feel at home'		4=92% (n=11) 2=8% (n=1)	4= 83% (n=10) 3=8.3% (n=1) 2=8.3% (n=1)

		2. Not quite sure what you mean by 'feel at home'. Needs further clarification or explanation. If it is home-based PC, how can you make somebody 'feel at home'?.		
26.	I make a difference to a person's day when I provide a palliative approach.13	-	4=100% (n=12)	4=100% (n=12)
27.	Seeing people who are not going to get better being fed through a feeding tube distresses me. DELETE	1. Difficult one. If it improves their QOL, it would not distress me. Futility, however, is another issue altogether. 'Not going to get better' could still be a reasonable period of life left. Depends on the circumstances. Difficult to answer with clarity. Seeing somebody being fed through a feeding tube who has probably only a few days to live might distress me. 11. That is the hospitals and families decision not mine	4= 75% (n=9) 3=16.7% (n=2) 2=8.3% (n=1)	4=66.7% (n=8) 3=25% (n=3) 2=8.3% (n=1)
28.	Pain medication should only be given when needed in a palliative approach. DELETE	1. Do you mean breakthrough pain medication? 2. Not sure about this question. Any medication should only be given when it is needed.	4=50% (n=6) 3=25% (n=3) 2=16.7%	4=66.7% (n=8) 3=16.7% (n=2) 2=16.7%

		3.	This concerns me as 'when needed' is ambiguous—if being given for pre-emptive pain then it may not be deemed as 'needed' at the time but should be given to prevent the pain occurring during a care procedure—I think 'Pain medication should always be given when needed in a palliative approach'.		(n=2) 1=8.3% (n=1) (n=2)
		12.	Attitudes to pain medication are one of the biggest issues in providing a PA and i think a question is needed but not one that tinkers around the edges of ethical decision making		
29.	I have a role to play in pain management.14	1.	I have a role to play in pain assessment and management	I have a role to play in pain assessment and management.	4=92% (n=11) 3=8% (n=1) 4=100% (n=12)
30.	A palliative approach in an aged care facility is not as effective as specialist palliative care. DELETE	1.	Maybe: 'A palliative approach in an aged care facility is often not as effective as specialist palliative care'.		4=66.7% (n=7) 3=25% (n=3) 1=8.3% (n=1) 4=75% (n=9) 3=8.3% (n=1) 2=16.7% (n=2)
		2.	Some staff may not have experienced specialist palliative care.		
31.	I always encourage palliative	1.	This question is a bit open to		4=75% 4=75% (n=9)

	care residents to eat even if they lack interest. DELETE	interpretation. Food and fluids should be offered while a person is able to swallow but refusal to accept OK too. 2. You have moved from palliative approach to palliative care and this is problematic in that palliative care is often associated with being close to death where PA is more about the last 12 months or so of life—maybe 3. when providing a palliative approach it is important for people to eat as much as they can' which opens up attitudes about food and intake being such an important part of life and poor recognition of the body shutting down and not needing so much food?		(n=9) 3=16.6% (n=2) 2=8.3% (n=1)	3=16.7% (n=2) 2=8.3% (n=1)
32.	Understanding a person's attitudes, beliefs and culture helps me when I am providing a palliative approach.15	-	Understanding a person's attitudes, beliefs and culture helps me provide care with a palliative approach.	4=100% (n=12)	4=100% (n=12)
33.	When I provide a palliative approach, I think about the person holistically.16	1. What is holistically 13. palliative / care approach—need to clarify what you mean as PA is	When I provide a palliative approach, I think about the whole person.	4= 83.3% (n=10) 3=9% (n=1)	4=92% (n=11) 3=8% (n=1)

	no PC		2=8.3% (n=1)	
34. In a palliative approach professional development is not necessary when care providers can learn on the job. DELETE	14. I think the issue I have with some of these statements is that they are missing a comma. i.e. In a palliative approach, professional development..... 15. We all need to learn things		4=85% (n=9) 3=16.6% (n=2) 2=8.3% (n=1)	4= 83.3% (n=10) 3=8.3% (n=1) 1=8.3% (n=1)
35. Sharing experiences with colleagues is important when providing a palliative approach.17	Great question might need to put in the word—confidentially	Privately sharing experiences with colleagues is important when providing a palliative approach.	4=83.3% (n=10) 3=16.7% (n=2)	4=83.3% (n=10) 3=16.7% (n=2)
36. I work well in a team providing a palliative approach.18	-		4=100% (n=12)	4=100% (n=12)
Is there any other content relevant to the attitudes of nursing assistants that you think should be included in this questionnaire?	Possibly around what training they have received and if they believe it needs to be a priority I feel comfortable when a resident decides they do not want any more treatment and are saying they are ready to die" I find it hard when a person stops eating and drinking for days before they actually die" Family should be involved as much as	Training in a palliative approach is a priority for my role. I feel comfortable when an individual receiving a palliative approach says that they are ready to die. I find it hard when a person stops eating and drinking in the days before they die.	No=83.3% (n=10) Yes=16.7% (n=2)	

	possible in caring for a person with a palliative approach.	
Is the design and format of this questionnaire user friendly?		Yes=91.6 (n=11) No=8.3% (n=1)

Appendix 8 Phase 3: Pilot study

Survey Administration Instructions

The steps below are provided to ensure that participant confidentiality is maintained throughout the survey process.

- Use only original paper surveys supplied by the researcher
- Access the online survey using the following link:
- https://www.surveymonkey.com/r/PILOT2PANA_Knowledge-Skills-Attitudes

Please note that you can complete *either* the paper survey *or* the online survey but not both.

Step 1

- Receive the paper survey and envelope from the person responsible in your facility.
- Indicate your preference to receive the link to the online survey via email (or type in the link above – please note the underscore (-) between PANA_Knowledge).

Step 2

- Please complete the survey on your **own** either in work time (if permitted) or at home.
- Please do not discuss your answer options with other staff members.

Step 3

- Place completed paper survey in confidential envelope provided and seal.
- Return sealed envelopes to the person responsible.
- If completing online, you will automatically exit the survey once you have submitted.

Please return completed surveys by **Tuesday 30 June 2015**

Thank you for your cooperation.

Usability Results: PANA_Knowledge Questionnaire

Questions	Site A	Site B
Was the questionnaire easy to complete?	Yes 96.6 % (n=29) No 3.3% (n=1)	Yes 93.5% (n=29) No 6.54 (n=2)[1,2,]
Were the questions clear and easy to understand?	Yes 90% (n=27) No 10% (n=3)	Yes 96.7% (n=30) No 3.23% (n=1)
Did the questions flow logically?	Yes 96.6 % (n=29) No 3.3% (n=1)	Yes 100% (n=31)
How long did the questionnaire take you to complete?	5 minutes = 36.7% (n=11) 10 minutes = 36.7% (n=11) 15 minutes = 10% (n=3) 20 minutes = 13.3 % (n=4) >20 minutes = 3.3% (n=1)	5 minutes = 22.5% (n=7) 10 minutes = 35.4% (n=11) 15 minutes = 19.3% (n=6) 20 minutes = 19.3 % (n=6) >20 minutes = 3.2% (n=1)
Do you think the questions were a mix of easy, moderately difficult and difficult questions?	Yes = 90% (n=27) No = 10% (n=10) [3, 4]	Yes = 87.1% (n=27) No = 12.9% (n=4)[5,6]
Other comments and suggestions	[3]I found them easy to moderately difficult [4]Pretty easy [7] To answer these questions, you should be a	[1]Some questions could not understand [2]Some questions make you think [5] I experienced no difficulty answering any of

	nurse for more than three years and above.	the questions [6] I found them quite easy because l have just completed a semester studying palliative care [8] Many women entering aged care as AiNs are of many diverse cultures. Their English is not good. Many speak their own language at home. This can and does cause a lack of understanding on their part. They are able to provide the personal care but lack the discernment and ability to communicate changes in residents conditions. As this trend continues in my opinion the quality of care deteriorates. [9]Thank you! I enjoyed doing this questionnaire [10]Thank you for the opportunity. I look forward to maybe assisting you in the future.

Usability Results: PANA_Skills Questionnaire

Questions	Pilot 1	Pilot 2
Was the questionnaire easy to complete?	Yes 100 % (n=30)	Yes 93.5% (n=28) No 6.4% (n=2)
Were the questions clear and easy to understand?	Yes 100 % (n=30)	Yes 100 % (n=31)
Did the questions flow logically?	Yes 96.5 % (n=28) No 3.45% (n=1)	Yes 100 % (n=30)
How long did the questionnaire take you to complete?	5 minutes = 48.2% (n=14) 10 minutes = 34.4% (n=10) 15 minutes = 10.3% (n=3) 20 minutes = 3.4 % (n=1) >20 minutes = 3.4% (n=1)	5 minutes = 25.8 % (n=8) 10 minutes = 41.9% (n=18) 15 minutes = 22.5% (n=7) 20 minutes = 3.2 % (n=1) >20 minutes = 6.4% (n=2)
Were the answer options adequate?	Yes 79.3% (n=23) No 20.6 % (n=6)	Yes 100% (n=31)
Other comments and suggestions	1.Some did not meet answer criteria 2. Not enough scope 3. The answer don't go with the question	1. This section would be very difficult for nurses with poor English skills. 2. Thank you I enjoyed doing this questionnaire.

Usability Results: PANA_Attitudes Questionnaire

Questions	Pilot 1	Pilot 2
Was the questionnaire easy to complete?	Yes 100 % (n=27)	Yes 100 % (n=30)
Were the questions clear and easy to understand?	Yes 100 % (n=27)	Yes 100 % (n=30)
Did the questions flow logically?	Yes 100 % (n=27)	Yes 100 % (n=30)
How long did the questionnaire take you to complete?	5 minutes = 55.5% (n=15) 10 minutes = 33.3% (n=9) 15 minutes = 7.4% (n=2) 20 minutes =0.00% >20 minutes = 3.7% (n=1)	5 minutes = 33.3 % (n=10) 10 minutes = 40.0% (n=12) 15 minutes = 20.0% (n=6) 20 minutes = 3.3 % (n=1) >20 minutes = 3.3% (n=1)
Were the answer options adequate?	Yes 96.3% (n=27) No 3.7 % (n=1)	Yes 96.7% (n=29) No 3.3 (n=1)
Other comments and suggestions		1. Sharing experiences with other staff always needs to be done in a professional way i.e. confidential that benefits the

	resident or the quality of care that is given to a resident; these discussions should be done privately. Sorry just a thought. 2. Majority of AiNs have no idea how to provide palliative care. Additional training to understand palliative care needs to be included in Cert 3 and 4. When I did Certs approx. 15 years ago very little was mentioned. I have learned a lot from my RN I have worked under last 10 years.

Means By Group: PANA_Knowledge Questionnaire

Group	**Mean positive responses by group (%) [SD] Pilot 1/Site A***	**Mean positive responses by group (%) [SD] Pilot 2/Site B**
Group 1 (<2 years experience)	23.6 (83.6) (n=10) [5.91]	25.5 (87.5) (n=2) [0.70]
Group 2 (2-5 years experience)	23.7 (83.6) (n=10) [10.0]	22 (85.7) (n=7) [1.41]
Group 3 (5+ years experience)	22.8 (81.7) (n=10) [4.89]	24.7 (88.3) (n=22) [1.38]
Range	19-25	16-26
Total mean number correct responses (%)	23.43 (83.6) [5.91]	22.6 (80.9)
Standard deviation (%)	1.65 [5.91]	2.42 [8.66]
95% confidence intervals (lower-upper)	0.59 (22.84-24.03)	0.84 (21.82-23.53)

Means By Group: PANA_Skills Questionnaire

Group	**Mean positive responses by group (%) [SD] Pilot 1/Site A***	**Mean positive responses by group (%) [SD] Pilot 2/Site B**
Group 1 (<2 years experience)	35.5 (93.5) (n=9)[2.00]	37 (97.3) (n=2) [1.41]
Group 2 (between 2-5 years experience)	37.7 (99.2) (n=10)[0.67]	34.4 (90.6) (n=7)[4.57]
Group 3 (>5 years experience)	36.6 (96.4) (n=9)[1.41]	35.7 (94.1) (n=22)[1.56]
Range	32-38	22-38
Total mean positive responses (%)	37 (96.6)	35.5 (93.5)
Standard deviation	1.645265	3.81
95% confidence intervals (upper, lower)	0.598804 (36,37)	1.344571 (34.2-36.8)

*Note: 10% missing data for skill items

Means By Group: PANA_Attitudes Questionnaire

Group	Pilot 1/Site A Mean positive responses by group (%) [SD]	Pilot 2/Site B Mean positive responses by group (%) [SD]
Group 1 (<2 years experience)	15.6 (82.4) (n=9*) [0.86] (95% CI: 0.56)	16.5 (86.8) (n=2) [2.13] (95% CI: 2.93)
Group 2 (between 2-5 years experience)*	15.8 (83.6) (n=9*) [1.9] (95% CI: 1.24)	11(57.8) (n=7) [3.10] (95% CI: 2.30)
Group 3 (>5 years experience)	16 (84.2) (n=8*) [SD .92] (95% CI: .64)	13.2 (69.9) (n=22) [3.25] (95% CI: 1.39)
Range	12-18	6-18
Total mean positive responses (%) [SD]	15.8 (83.62) [1.281025]	12.9 (68.2) [3.36]
95% confidence interval	0.483197 (15.4-16.3)	1.205215 (11.7-14.1)

Note: *10-20% missing data for Attitudes Site A

Results of PANA_Knowledge Questionnaire for pilot study

	Group 1 < 2 years experience (n=10)		**Group 2 2-5 years experience (n=6)**		**Group 2 2-5 years Online responses (n=4)**		**Group 3 5+ years experience (n=10)**		**Item difficulty (n=30)**
	Response (%)	Item difficulty	Response (%)	Item difficulty		Item difficulty	Response (%)	Item difficulty	Total
1. A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.									
T*	90.0	0.90	100	1.0	75.0	0.75	80.0	0.80	0.96
F	10.0		00		25.0		20.0		
DK	00		00		00		00		
2. A palliative approach supports comfort but does not provide a cure.									
T*	100	1.00	100	1.0	75.0	0.75	100	1.00	0.90
F	0		00		25.0		0		
DK	0		00		00		0		
3. A palliative approach may be required for some people for months or years while for others it may be required for hours or days.									

T*	80.0	0.80	100	1.0	100	1.0	90.0	0.90	0.90
F	20.0		00		00		10.0		
DK	00		00		00		00		

4. The needs of people requiring a palliative approach are the same.

T	0		0		100	1.0	40.0		0.83
F*	100	-1.00	100	-1.00	00		50.0	0.50	
DK	0		00		00		10.0#		

5. A palliative approach is offered when treatment will not help the person to live longer.

T*	100	1.0	100	1.0	25.0	0.25	80.0	0.80	0.83
F	00		00		75.0		10.0		
DK	00		00		00		10.0#		

6. People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative

approach.

T*	90.0	0.90	100	1.0	100	1.0	90.0	0.90	0.93
F	10.0		00		00		00		
DK			00		00		10.0#		

7. Frequently changing a person's position to prevent pressure sores is always necessary when a person is receiving a palliative approach.

T	90.0		100		100		90.0		0.03
F*	10.0	0.10	00	-1.00	00	-1.00	000	-1.00	
DK	0		00		00		10.0#		

8. Providing a palliative approach is based on the individual's needs and wishes.

T*	90.0	0.90	100	1.00	100	1.00	90.0	0.90	0.93
F	0		00		00		10.0		
DK	10.0		00		00		00		

9. Families need to understand what is happening and be involved in decision-making.									
T*	100	1.00	100	1.00	100	1.00	90.0	0.90	0.96
F	00		00		00		00		
DK	00		00		00		10.0#		
10. Families can often experience grief before the death of their family member.									
T*	100	1.00	100	1.00	100	1.00	100	1.00	100
F	00		00		00		00		
DK	00		00		00		00		
11. It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.									
T	40.0		33.3		75.0		60.0		0.43
F*	60.0	0.60	66.7	0.67	00	-1.00	30.0	0.30	
DK	0		00		25.0		10.0#		

12. The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.									
T*	90.0	0.90	100	1.0	75.0	0.75	90.0	0.90	0.90
F	10.0		00		25.0		00		
DK			00		00		10.0#		

13. Identifying symptoms (physical signs) is the first step in being able to manage symptoms.									
T*	80.0	0.80	100	1.0	100	1.0	90.0	0.90	0.93
F	10.0		00		00		10.0		
DK	10.0		00		00		00		

14. Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.									
T*	90.0	0.90	100	1.0	50.0	0.50	100	1.00	0.90
F	0		00		50.0		00		
DK	10.0		00		00		00		

15. When a person is receiving pain relief, they no longer feel pain.									
T	0		16.6		100	-1.00	30.0		
F*	100	1.00	83.3	0.83	00		60.0	0.60	0.83
DK	0		00		00		10.0#		
16. Pain can be caused by physical, psychological, social or spiritual distress									
T*	90.0	0.90	100	1.0	100	1.0	100	1.00	0.97
F	10.0		00		00		00		
DK	00		00		00		00		
17. Facial expressions, calling out and resisting care can be the result of pain.									
T*	100	1.00	100	1.0	100	1.0	100	1.00	100
F	0		00		00		0		
DK	0		00		00		0		

18. Families or carers who know the person best are usually the first to detect changes in a person's condition.									
T*	100	1.00	100	1.0	75.0	0.75	100	1.00	0.97
F	0		00		25.0		0		
DK	0		00		00		0		
19. A person expressing a wish to die means that the person will die soon.									
T	00		100		00		00		0.97
F*	90.0	0.90	100	1.0	100	1.0	100	1.00	
DK	10.0		00		00		00		
20. Working as a team when providing a palliative approach is important because individuals and their families may experience a broad range of issues.									
T*	100	1.0	100	1.0	100	1.0	100	1.00	100
F	00		00		00		00		
DK	00		00		00		00		

21. Respectful communication can improve how a person feels.									
T*	100	1.0	100	1.0	100	1.0	100	1.0	100
F	00		00		00		00		
DK	00		00		00		00		
22. Spiritual care identifies what is important to a person.									
T*	70.0	0.70	100	1.0	75.0	0.75	90.0	0.90	0.83
F	00		00		00		10.0		
DK	30.0		00		25.0		00		
23. Encouraging family to be involved in care is an important part of a palliative approach.									
T*	80.0	0.80	100	1.0	100	1.0	100	1.00	0.93
F	00		00		00		0		
DK	20.0		00		00		0		

24. Bladder and bowel problems can cause discomfort when a person approaches the end of life.									
T*	90.0	0.90	100	1.0	100	1.0	90.0	0.90	0.93
F	00		00		00		00		
DK	10.0		00		00		10.0#		
25. Dehydration is a problem when a person is close to death.									
T	80.0		100		100		70.0		0.06
F*	10.0	0.10	00	-1.00	00	-1.00	10.0	0.10	
DK	10.0		00		00		20.0#		
26. A dry mouth is one of the most common symptoms in a person who is no longer eating and drinking.									
T*	100	1.00	100	1.0	100	1.0	90.0	0.90	0.96
F	00		00		00		00		
DK	00		00		00		10.0#		

27. When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.									
T*	40.0	0.40	33.3	0.33	100	1.0	90.0	0.90	0.66
F	40.0		66.6		00		10.0		
DK	20.0		00		00		00		
28. Signs that death is near can be present hours to days before death occurs.									
T*	100	1.00	100	1.0	100	1.0	80.0	0.80	0.93
F	00		00		00		20.0		
DK	00		00		00		00		

Note: * = correct response

= missing data which is scored 'Don't Know' due to forced scoring in Survey Monkey

Appendix 9 Palliative Care Quiz for Nurses

1.	Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration (F)
2.	Morphine is the standard used to compare the analgesic effect of other opioids (T)
3.	The extent of the disease determines the method of pain treatment (F)
4.	Adjuvant therapies are important in managing pain (T)
5.	It is crucial for family members to remain at the bedside until death occurs (F)
6.	During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation (T)
7.	Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain (F)
8.	Individuals who are taking opioids should also follow a bowel regime (T)
9.	The provision of palliative care requires emotional detachment (F)
10.	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea (T)
11.	Men generally reconcile their grief more quickly than women (F)
12.	The philosophy of palliative care is compatible with that of aggressive treatment (T)
13.	The use of placebos is appropriate in the treatment of some types of pain (F)
14.	In high doses, codeine causes more nausea and vomiting than morphine (T)
15.	Suffering and physical pain are synonymous (F)
16.	Demerol (Pethidine) is not an effective analgesic in the control of chronic pain (T)
17.	The accumulation of losses renders burnout inevitable for those who seek work in palliative care (F)
18.	Manifestations of chronic pain are different to those of acute pain (T)
19.	The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate (F)
20.	The pain threshold is lowered by anxiety or fatigue (T)

Appendix 10 Individual item analysis

Items removed from the PANA_Knowledge Questionnaire						
Item no.	**Item**	**Discrimination Index**	**Difficulty Index**	**Item-total correlation**	**Alpha if item removed**	**Final alpha**
7.	Frequently changing a person's position to prevent pressure sores is always necessary when a person is receiving a palliative approach.	4	.09	.46	.78	
8.	Providing a palliative approach is based on the individual's needs and wishes.	42	.95	.45	.78	
9.	Families need to understand what is happening and be involved in decision-making.	7	.98	.40	.79	
16.	Pain can be caused by physical, psychological, social or spiritual distress	11	.93	.35	.79	
17.	Facial expressions, calling out and resisting care can be the result of pain.	23	.94	.44	.78	
20.	Working as a team when providing a palliative approach is important because individuals and their families may experience a broad range of issues.	16	.94	.28	.79	
21.	Respectful communication can improve how a person feels.	0	.99	.19	.79	

22.	Spiritual care identifies what is important to a person.	21	.87	.14	0.80	0.72
23.	Encouraging family to be involved in care is an important part of a palliative approach.	23	.94	.19	.79	
25.	Dehydration is a problem when a person is close to death.	-9	.11	.34	.79	
26.	A dry mouth is one of the most common symptoms in a person who is no longer eating and drinking.	7	.97	.17	.79	

PANA_Knowledge Questionnaire item difficulty by group

Group 1 < 2 years experience (n=88)			**Group 2 2-5 years experience (n=116)**		**Group 3 5+ years experience (n=144)**	
Response (%)		Item difficulty	Response (%)	Item difficulty	Response (%)	Item difficulty
1. A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.						
T*	90.9	0.91	89.7	0.90	91.7	0.92
F	3.4		5.2		6.9	
DK	5.7		5.2		1.4	
2. A palliative approach supports comfort but does not provide a cure.						
T*	87.5	0.88	87.9	0.88	93.8	0.94
F	11.4		8.6		6.3	
DK	1.1		3.4		0.0	
3. A palliative approach may be required for some people for months or years while for others it may be required for hours or days.						
T*	87.5	0.88	87.1	0.87	92.4	0.92
F	11.4		7.8		4.2	
DK	1.1		5.2		3.5	
4. The needs of people requiring a palliative approach are the same.						
T	27.3		26.7		33.3	
F*	67.0	0.67	66.4	0.66	64.6	0.65
DK	5.7		6.9		2.1	
16. A palliative approach is offered when treatment will not help the person to live longer.						
T*	78.4	0.79	81.9	0.82	86.1	0.86
F	19.3		10.3		13.2	
DK	2.3		7.8		0.7	
5. People who have advanced cancer, severe lung or heart or kidney disease or						

advanced dementia benefit from a palliative approach.

T*	76.1	0.76	78.4	0.78	81.3	0.81
F	12.5		11.2		6.3	
DK	11.4		10.3		12.5	

6. Frequently changing a person's position to prevent pressure sores is always necessary when a person is receiving a palliative approach.

T	86.4		85.3		88.9	
F*	9.1	0.09	6.0	0.06	9.0	0.09
DK	4.5		8.6		2.1	

7. Providing a palliative approach is based on the individual's needs and wishes.

T*	94.3	0.94	94.8	0.95	95.8	0.96
F	4.5		1.7		2.8	
DK	1.1		3.4		1.4	

8. Families need to understand what is happening and be involved in decision-making.

T*	96.6	0.97	97.4	0.97	100.0	0.100
F	2.3		0.9		0.0	
DK	1.1		1.7		0.0	

9. Families can often experience grief before the death of their family member.

T*	89.8	0.90	88.8	0.89	94.4	0.94
F	6.8		3.4		2.8	
DK	3.4		7.8		2.8	

10. It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.

T	62.5		57.8		67.4	
F*	33.0	0.33	32.8	0.33	27.8	0.28
DK	4.5		9.5		4.9	

11. The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer

swallow safely.

T*	92.0	0.92	86.2	0.86	93.1	0.93
F	6.8		3.4		6.9	
DK	1.1		10.3		0.0	

12. Identifying symptoms (physical signs) is the first step in being able to manage symptoms.

T*	85.2	0.85	88.8	0.89	87.5	0.88
F	8.0		5.2		7.6	
DK	6.8		6.0		4.9	

13. Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.

T*	85.2	0.85	87.9	0.88	92.4	0.92
F	8.0		3.4		4.9	
DK	6.8		8.6		2.8	

14. When a person is receiving pain relief, they no longer feel pain.

T	15.9		21.6		24.3	
F*	81.8	0.81	74.1	0.74	74.7	0.75
DK	2.3		4.3		4.0	

15. Pain can be caused by physical, psychological, social or spiritual distress

T*	94.3	0.94	91.4	0.91	95.8	0.96
F	1.1		5.2		3.5	
DK	4.5		3.4		0.7	

16. Facial expressions, calling out and resisting care can be the result of pain.

T*	90.9	0.91	94.0	0.94	96.5	0.97
F	6.8		1.7		2.1	
DK	2.3		4.3		1.4	

17. Families or carers who know the person best are usually the first to detect changes

in a person's condition.

T*	88.6	0.89	90.5	0.91	93.1	0.93
F	8.0		5.2		5.6	
DK	3.4		4.3		1.4	

18. A person expressing a wish to die means that the person will die soon.

T	12.5		12.9		11.8	
F*	81.8	0.82	81.9	0.82	81.3	0.81
DK	5.7		5.2		6.9	

19. Working as a team when providing a palliative approach is important because individuals and their families may experience a broad range of issues.

T*	93.2	0.93	95.7	0.96	92.4	0.92
F	1.1		0.9		2.8	
DK	5.7		3.4		4.9	

20. Respectful communication can improve how a person feels.

T*	98.9	0.99	99.1	0.99	100.0	0.100
F	0.0		0.9		0.0	
DK	1.1		0.0		0.0	

21. Spiritual care identifies what is important to a person.

T*	85.2	0.85	79.3	0.79	91.0	0.91
F	5.7		12.1		4.2	
DK	9.1		8.6		4.9	

22. Encouraging family to be involved in care is an important part of a palliative approach.

T*	90.9	0.91	94.8	0.95	95.8	0.96
F	4.5		1.7		2.1	
DK	4.5		3.4		2.1	

23. Bladder and bowel problems can cause discomfort when a person approaches the

end of life.

T*	85.2	0.85	85.3	0.85	94.4	0.94
F	4.5		7.8		2.8	
DK	10.2		6.9		2.8	

24. Dehydration is a problem when a person is close to death.

T	83.0		77.6		86.8	
F*	12.5	0.13	12.9	0.13	9.0	0.09
DK	4.5		9.5		4.2	

25. A dry mouth is one of the most common symptoms in a person who is no longer eating and drinking.

T*	92.0	0.92	97.4	0.97	95.8	0.96
F	4.5		1.7		2.1	
DK	3.4		0.9		2.1	

26. When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.

T*	67.0	0.67	71.6	0.72	75.0	0.75
F	18.2		19.0		15.3	
DK	14.8		9.5		9.7	

27. Signs that death is near can be present hours to days before death occurs.

T*	71.6	0.72	72.4	0.72	83.3	0.83
F	14.8		12.1		6.9	
DK	13.6		15.5		9.7	

Note: * = correct response.

Total correct responses for each item across all participants

1. 91%*	2. 90%	3. 89%	4. 66%	5. 83%
6. 79%	7. 8%	8. 95%	9. 98%	10. 91%*
11. 31%	12. 91%*	13. 87%	14. 89%	15. 75%
16. 94%	17. 94%	18. 91%*	19. 82%	20. 94%
21. 99%	22. 86%	23. 94%	24. 89%	25. 11%
26. 95%	27. 72%	28. 77%		

Note: Based on the item difficulty index of 0.1 and 0.9, nine items were identified for removal: 7, 8, 9, 16, 17, 20, 21, 23,26.

* Items which had ≤.9 in one of the subgroups were retained.

Items Removed from the PANA_Skills Questionnaire

Item no.	Item	Discrimination Index %	Item-total correlation	Alpha if item removed	Final Alpha
2.	Provide care based on a person's care plan	19	.52	.93	
4.	Demonstrate understanding in the care I provide	16	.54	.93	
5.	Build a relationship with the people I care for	7	.59	.93	
6.	Listen attentively to the people I care for	9	.63	.93	
7.	Support families by addressing their concerns or report these concerns to a more senior person	16	.59	.93	
8.	Communicate with families by providing information appropriate to my level of understanding	12	.47	.93	
10.	Support families when they are grieving by showing care and understanding	9	.45	.93	
11.	Report the needs of individuals to the registered nurse or person in charge	2	.69	.93	
12.	Maintain a person's safety	0	.65	.93	
15.	Ask an individual whether she/he has pain	5	.61	.93	
17.	Report pain to the registered nurse or person in charge	0	.69	.93	
20.	Observe for problems with an individual's skin, such as a pressure area	9	.48	.93	
21.	Monitor for bladder or bowel problems, such as strong-smelling urine or constipation	16	.51	.93	
22.	Monitor and report new or increasing confusion.	14	.65	.93	
23.	Monitor and report problems or changes in an individual's breathing, such as noisy breathing	14	.72	.93	

24.	Monitor and report any physical, emotional or behavioural changes	5	.65	.93
25.	Provide both physical and emotional comfort depending on individual need	5	.60	.93
26.	Position people for comfort	5	.63	.93
28.	Support team members to the best of my ability	7	.68	.93
30.	Provide privacy for a dying person and his/her family	5	.57	.93
32.	Demonstrate care and respect right until the end of a person's life	16	.62	.93
34.	Provide individualised personal care	7	.62	.93
36.	Seek advice when I am unsure about how to do something	12	.48	.93
37.	Maintain a work-life balance for my own wellbeing	19	.52	.93
38.	Provide a palliative approach by supporting individuals in my care	14	.56	.93

PANA_Skills Questionnaire item difficulty by group

	Group 1 < 2 years experience (n=88)		**Group 2** 2-5 years experience (n=116)		**Group 3** 5+ years experience (n=142)	
	Response (%)	skill difficulty	Response (%)	skill difficulty	Response (%)	skill difficulty
1. Observe what a person can do without assistance						
I know how to do this	94.3	0 94	87.9	0 88	89.4	0 89
I am unsure how to do this	3.4		10.3		9.2	
I do not know how to do this	2.3		1.7		1.4	
2. Provide care based on a person's care plan						
I know how to do this	89.8	0.90	97.4	0 97	93.0	0 93
I am unsure how to do this	9.1		2.6		4.2	
I do not know how to do this	1.1		0.0		2.8	
3. Assist with updating care plans						
I know how to do this	76.1	0 76	72.4	0 72	83.1	0 83
I am unsure how to do this	19.3		20.7		13.4	
I do not know how to do this	4.5		6.9		3.5	
4. Demonstrate understanding in the care I provide						
I know how to do this	93.2	0 93	96.6	0 97	90.8	0 91
I am unsure how to do this	5.7		3.4		7.7	
I do not know how to do this	1.1		0.0		1.4	
5. Build a relationship with the people I care for						
I know how to do this	93.2	0 93	96.6	0 97	98.6	0 99
I am unsure how to do this	5.7		2.6		0.7	
I do not know how to do this	1.1		0.9		0.7	
6. Listen attentively to the people I care for						
I know how to do this	94.3	0 94	97.4	0 97	97.9	0 98
I am unsure how to do this	4.5		1.7		1.4	
I do not know how to do this	1.1		0.9		0.7	
7. Support families by addressing their concerns or report these concerns to a more senior person						
I know how to do this	92.0	0 92	95.7	0 96	96.5	0 97
I am unsure how to do this	6.8		4.3		2.8	
I do not know how to do this	1.1		0.0		0.7	

8. Communicate with families by providing information appropriate to my level of understanding						
I know how to do this	93.2	0 93	95.7	0 96	92.3	0 92
I am unsure how to do this	5.7		3.4		6.3	
I do not know how to do this	1.1		0.9		1.4	
9. Direct families to other members of the care team when they need further advice						
I know how to do this	83.0	0 83	93.1	0 93	86.6	0 87
I am unsure how to do this	15.9		6.9		11.3	
I do not know how to do this	1.1		0.0		2.1	
10. Support families when they are grieving by showing care and understanding						
I know how to do this	92.0	0 92	91.4	0 91	93.4	0 93
I am unsure how to do this	8.0		8.6		6.4	
I do not know how to do this	0.0		0.0		0.3	
11. Report the needs of individuals to the registered nurse or person in charge						
I know how to do this	96.6	0 97	98.3	0 98	99.3	0 99
I am unsure how to do this	3.4		1.7		0.0	
I do not know how to do this	0.0		0.0		0.7	
12. Maintain a person's safety						
I know how to do this	95.5	0 96	99.1	0 99	98.6	0 99
I am unsure how to do this	4.5		0.9		0.7	
I do not know how to do this	0.0		0.0		0.7	
13. Care for a person with challenging behaviours						
I know how to do this	85.2	0 85	91.4	0 91	91.5	0 92
I am unsure how to do this	14.8		8.6		7.7	
I do not know how to do this	0.0		0.0		0.7	
14. Raise the concerns of (advocate for) the individuals in my care						
I know how to do this	86.4	0 86	90.5	0 91	91.5	0 92
I am unsure how to do this	13.6		9.5		7.0	
I do not know how to do this	0.0		0.0		1.4	
15. Ask an individual whether she/he has pain						
I know how to do this	95.5	0 96	98.3	0 98	97.9	0 98
I am unsure how to do this	4.5		1.7		1.4	
I do not know how to do this	0.0		0.0		0.7	
16. Observe for pain using a valid and reliable pain assessment tool						
I know how to do this	72.7	0 73	69.8	0 70	76.1	076
I am unsure how to do this	25.0		24.1		20.4	
I do not know how to do this	2.3		6.0		3.5	

17. Report pain to the registered nurse or person in charge						
I know how to do this	97.7	0 98	98.3	0 98	99.3	0 99
I am unsure how to do this	2.3		1.7		0.0	
I do not know how to do this	0.0		0.0		0.7	
18. Provide non-medication strategies, such as gentle massage, in order to manage pain						
I know how to do this	81.8	0 82	81.0	0 81	88.0	0 88
I am unsure how to do this	14.8		16.4		9.9	
I do not know how to do this	3.4		2.6		2.1	
19. Evaluate the effectiveness of pain management strategies using a validated pain assessment tool						
I know how to do this	62.5	0 63	56.8	0 57	65.5	0 66
I am unsure how to do this	34.1		32.8		29.6	
I do not know how to do this	3.4		9.5		4.9	
20. Observe for problems with an individual's skin, such as a pressure area						
I know how to do this	93.2	0 93	95.7	0 96	96.5	0 97
I am unsure how to do this	5.7		3.4		2.8	
I do not know how to do this	1.1		0.9		0.7	
21. Monitor for bladder or bowel problems, such as strong-smelling urine or constipation						
I know how to do this	95.5	0 96	94.8	0 95	93.7	0 94
I am unsure how to do this	4.5		3.4		4.2	
I do not know how to do this	0.0		1.7		2.1	
22. Monitor and report new or increasing confusion						
I know how to do this	93.2	0 93	94.8	0 95	96.5	0 97
I am unsure how to do this	6.8		3.2		2.8	
I do not know how to do this	0.0		1.7		0.7	
23. Monitor and report problems or changes in an individual's breathing, such as noisy breathing						
I know how to do this	96.6	0 97	94.8	0 95	95.1	0 95
I am unsure how to do this	3.4		5.2		4.2	
I do not know how to do this	0.0		0.0		0.7	
24. Monitor and report any physical, emotional or behavioural changes						
I know how to do this	96.6	0 97	97.4	0 97	96.5	0 97
I am unsure how to do this	3.4		2.6		2.8	
I do not know how to do this	0.0		0.0		0.7	
25. Provide both physical and emotional comfort depending on individual need						
I know how to do this	92.0	0 92	94.8	0 95	97.2	0 97
I am unsure how to do this	6.8		5.2		2.1	
I do not know how to	1.1		0.0		0.7	

do this						
26. Position people for comfort						
I know how to do this	97.7	0 98	97.4	0 97	97.9	0 98
I am unsure how to do this	2.3		2.6		1.4	
I do not know how to do this	0.0		0.0		0.7	
27. Contribute to problem solving to seek solutions						
I know how to do this	89.8	0 90	87.1	0 87	91.5	0 92
I am unsure how to do this	8.0		12.1		7.7	
I do not know how to do this	2.3		0.9		0.7	
28. Support team members to the best of my ability						
I know how to do this	97.7	0 98	96.6	0 97	98.6	0 99
I am unsure how to do this	2.3		3.4		0.7	
I do not know how to do this	0.0		0.0		0.7	
29. Recognise the signs when an individual is in the last days or hours of life						
I know how to do this	76.1	0 76	77.6	0 78	86.6	0 87
I am unsure how to do this	21.6		19.8		11.3	
I do not know how to do this	2.3		2.6		2.1	
30. Provide privacy for a dying person and his/her family						
I know how to do this	97.7	0 98	96.6	0 97	97.2	0 97
I am unsure how to do this	2.3		3.4		1.4	
I do not know how to do this	0.0		0.0		1.4	
31. Attend to a dying individual's care						
I know how to do this	84.1	0 84	92.2	0 92	94.4	0 94
I am unsure how to do this	14.8		4.3		2.8	
I do not know how to do this	1.1		3.4		2.8	
32. Demonstrate care and respect right until the end of a person's life						
I know how to do this	93.2	0 93	95.7	0 96	97.2	0 97
I am unsure how to do this	6.8		2.6		2.6	
I do not know how to do this	0.0		1.7		2.1	
33. Find ways to cope with my own emotional responses when a person I have been caring for has died						
I know how to do this	87.5	0 88	92.2	0 92	93.7	0 94
I am unsure how to do this	10.2		7.8		3.5	
I do not know how to do this	2.3		0.0		2.8	
34. Provide individualised personal care						
I know how to do this	96.6	0 97	97.4	0 97	95.8	0 96
I am unsure how to do this	3.4		2.6		2.8	
I do not know how to do this	0.0		0.0		1.4	

35. Reflect on what I say and do when providing a palliative approach						
I know how to do this	89.8	0 90	93.1	0 93	92.3	0 92
I am unsure how to do this	9.1		6.9		6.3	
I do not know how to do this	1.1		0.0		1.4	
36. Seek advice when I am unsure about how to do something						
I know how to do this	93.2	0 93	94.8	0 95	95.8	0 96
I am unsure how to do this	6.8		4.3		2.8	
I do not know how to do this	0.0		0.9		1.4	
37. Maintain a work-life balance for my own wellbeing						
I know how to do this	93.2	0 93	94.8	0 95	96.5	0 97
I am unsure how to do this	5.7		4.3		2.1	
I do not know how to do this	1.1		0.9		1.4	
38. Learn how to provide a palliative approach by supporting individuals in my care						
I know how to do this	95.5	0 96	97.4	0 97	93.7	0 94
I am unsure how to do this	4.5		2.6		4.9	
I do not know how to do this	0.0		0.0.		1.4	

Items removed from the PANA_Attitudes Questionnaire

Item no.	Item	Discrimi-nation Index %	Item-total correlation	Alpha if item removed
2.	In a palliative approach, people are best cared for in bed	14	-.143	.81
3.	Spending time with a person who is approaching the end of life is hard	40	-.143	.80
5.	Explaining the purpose of my care demonstrates respect even when an individual is unable to respond	7	.59	.75
8.	In a palliative approach, families need my support	9	.46	.76
9.	I find it hard to control my emotions when families are grieving	30	-.121	.81
12.	A caring attitude improves the quality of a palliative approach	9	.67	.75
15.	Understanding a person's attitudes, beliefs and culture helps me provide care with a palliative approach	7	.69	.75
18.	I work well in a team providing care with a palliative approach	9	.34	.75
19.	Training in a palliative approach is a priority for my role	9	.45	.76

Appendix 11 Principal components analysis

Factor structure of the PANA_KSAq

	Item	Component					
		1	2	3	4	5	h^2
Component 1: Skills for a palliative approach							
19	Evaluate the effectiveness of pain management strategies using a validated pain assessment tool	0.737	-.129	-.029	-.046	0.047	0.556
16	Observe for pain using a valid and reliable pain assessment tool	0.639	-.074	0.079	-.087	0.153	0.487
14	Raise the concerns of (advocate for) the individuals in my care	0.594	-.005	.012	.097	-.247	0.380
27	Contribute to problem solving to seek solutions	0.529	0.036	-.096	.129	0.028	0.319
9	Direct families to other members of the care team when they need further advice	0.523	0.157	0.165	-.046	0.043	0.360
3	Assist in updating care plans	0.522	0.025	0.042	0.134	-.113	0.310
29	Recognise the signs when an individual is in the last days or hours of life	0.447	-.028	-.072	0.067	0.351	0.393
13	Care for a person with challenging behaviours	0.447	.005	0.020	0.104	0.277	0.362
18	Provide non-medication strategies, such as gentle massage, in order to manage pain	0.430	-.019	0.237	-.066	0.267	0.400
35	Reflect on what I say and do when providing a palliative approach	0.377	0.196	0.022	0.140	0.334	0.383

Component 2: Challenges of care							
19	A person expressing a wish to die means that the person will die soon.	-.065	0.655	0.067	0.032	0.098	0.430
15	When a person is receiving pain relief, they no longer feel pain.	-.170	0.642	0.152	-.028	0.068	0.445
4	The needs of people requiring a palliative approach are the same.	-.001	0.616	0.069	0.054	-.072	0.393
9	I find it hard to control my emotions when families are grieving	0.121	0.547	-.173	-.351	0.188	0.505
3	Spending time with a person who is approaching the end of life is hard	0.201	0.498	-.113	-.223	0.058	0.358
11	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.	0.120	0.411	-.037	0.100	-.157	0.222
27	When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.	0.109	-.340	0.122	-.111	0.272	0.263
Component 3: Detecting changes							
10	Families often experience grief before the death of their family member	-.172	0.011	0.570	0.114	-.034	0.346
18	Families or carers who know the person best are usually the first to detect changes in a person's condition	-.005	0.008	0.560	0.033	-.089	0.311

12	The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.	0.110	-.057	0.515	-.025	-.185	0.289
1	A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.	0.067	0.051	0.513	0.019	-.133	0.277
3	A palliative approach may be required for some people for months or years while for others it may be required for hours or days.	-.202	0.038	0.490	0.052	0.266	0.346
24	Bladder and bowel problems can cause discomfort when a person approaches the end of life.	-.010	-.080	0.487	0.045	0.059	0.268
14	Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.	0.198	-.004	0.480	0.019	-.177	0.292
13	Identifying symptoms (physical signs) is the first step in being able to manage symptoms.	-.018	0.088	0.390	0.096	0.130	0.205
5	A palliative approach is offered when treatment will not help the person to live longer.	0.020	-.092	0.387	-.075	0.197	0.224
2	A palliative approach supports comfort but does not provide a	0.001	0.052	0.371	-.103	0.060	0.150

	cure.						
6	People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative approach.	0.094	0.014	0.354	0.149	0.136	0.224
Component 4: Making a difference							
13.	I make a difference to a person's day when I provide care with a palliative approach	0.028	0.096	0.073	0.741	0.161	0.618
14.	I have an important role to play in pain assessment and management	0.245	0.058	-.007	0.617	0.006	0.490
4.	Being aware of a person's emotional, social and spiritual needs is my responsibility	-.008	0.033	0.173	0.572	-.045	0.377
17.	Privately sharing experiences with colleagues is important when providing a palliative approach	0.197	-.232	-.009	0.493	0.020	0.381
11.	I feel comfortable when an individual receiving a palliative approach says they are ready to die	-.054	-.135	-.093	0.488	0.404	0.428
Component 5: End-of-life care							
31	Attend to a dying individual's care	0.089	-.032	-.079	0.143	0.667	0.505
33	Find ways to cope with my own emotional responses when a person I have been caring for has died	0.092	0.057	0.062	0.093	0.629	0.463

28	Signs that death is near can be present hours to days before death occurs.	0.187	-.115	0.209	-.171	0.326	0.263
Eigenvalues		5.13	2.47	2.31	1.67	1.42	
% of variance		14.2	6.87	6.42	4.63	3.95	
Alpha		0.79	0.45	0.67	0.52	0.43	

Principal Components Analysis to support divergence between the PANA_Knowledge Questionnaire and the PCQN

```
FACTOR
/VARIABLES K1 K2 K3 K4 K5 K6 K10 K11 K12 K13 K14 K15 K18 K19 K22 K24
K27 K28 PCQN1 PCQN2 PCQN3 PCQN4 PCQN5 PCQN6 PCQN7 PCQN8 PCQN9
PCQN10 PCQN11 PCQN12 PCQN13 PCQN14 PCQN15 PCQN16 PCQN17 PCQN18
PCQN19 PCQN20
/MISSING LISTWISE
/ANALYSIS K1 K2 K3 K4 K5 K6 K10 K11 K12 K13 K14 K15 K18 K19 K22 K24
K27 K28 PCQN1 PCQN2 PCQN3 PCQN4 PCQN5 PCQN6 PCQN7 PCQN8 PCQN9
PCQN10 PCQN11 PCQN12 PCQN13 PCQN14 PCQN15 PCQN16 PCQN17 PCQN18
PCQN19 PCQN20
/PRINT ROTATION
/FORMAT SORT
/CRITERIA FACTORS(2) ITERATE(25)
/EXTRACTION PC
/CRITERIA ITERATE(25)
/ROTATION VARIMAX
/METHOD=CORRELATION.
```

Rotated Component Matrix[a]	**Component**	
	1	2
8. Individuals who are taking opioids should also follow a bowel regime	.557	-.268
6. People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative approach.	.515	.060
14. Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.	.502	.020
12. The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely.	.495	.066
13. Identifying symptoms (physical signs) is the first step in being able to manage symptoms.	.487	.049
1. A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.	.467	.143

2. A palliative approach supports comfort but does not provide a cure.	.467	.115
3. A palliative approach may be required for some people for months or years while for others it may be required for hours or days.	.426	.149
18. Families or carers who know the person best are usually the first to detect changes in a person's condition.	.423	.042
2. Morphine is the standard used to compare the analgesic effect of other opioids	.410	-.349
18. Manifestations of chronic pain are different to those of acute pain	.406	-.346
10. Families often experience grief before the death of their family member.	.386	.069
24. Bladder and bowel problems can cause discomfort when a person approaches the end of life.	.373	.063
5. A palliative approach is offered when treatment will not help the person to live longer.	.373	.047
28. Signs that death is near can be present hours to days before death occurs.	.349	-.055
27. When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.	.265	-.227
22. Spiritual care identifies what is important to a person.	.246	-.137
13. The use of placebos is appropriate in the treatment of some types of pain	.225	.127
12. The philosophy of palliative care is compatible with that of aggressive treatment	.191	-.586
10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	.363	-.568
16. Demerol (Pethidine) is not an effective analgesic in the control	.315	-.512

of chronic pain		
5. It is crucial for family members to remain at the bedside until death occurs	.123	.487
14. In high doses, codeine causes more nausea and vomiting than morphine	.382	-.479
15. When a person is receiving pain relief, they no longer feel pain.	.205	.462
20. The pain threshold is lowered by anxiety or fatigue	.236	-.447
6. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation	.406	-.438
9. The provision of palliative care requires emotional detachment	.173	.410
4. The needs of people requiring a palliative approach are the same.	.225	.394
4. Adjuvant therapies are important in managing pain	.369	-.385
19. A person expressing a wish to die means that the person will die soon.	.208	.379
1. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration	.051	.368
11. Men generally reconcile their grief more quickly than women	.139	.346
11. It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English.	.288	.301
17. The accumulation of losses renders burnout inevitable for those who seek work in palliative care	.222	.277
15. Suffering and physical pain are synonymous	.013	.254
7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	.051	.219
3. The extent of the disease determines the method of pain treatment	-.026	.216
19. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate	.042	.203

Extraction method: principal component analysis.

Rotation method: Varimax with Kaiser Normalization.[a]

Note: a. Rotation converged in 3 iterations.

Principal component analysis of the PANA_Attitudes Questionnaire

Scale Statistics

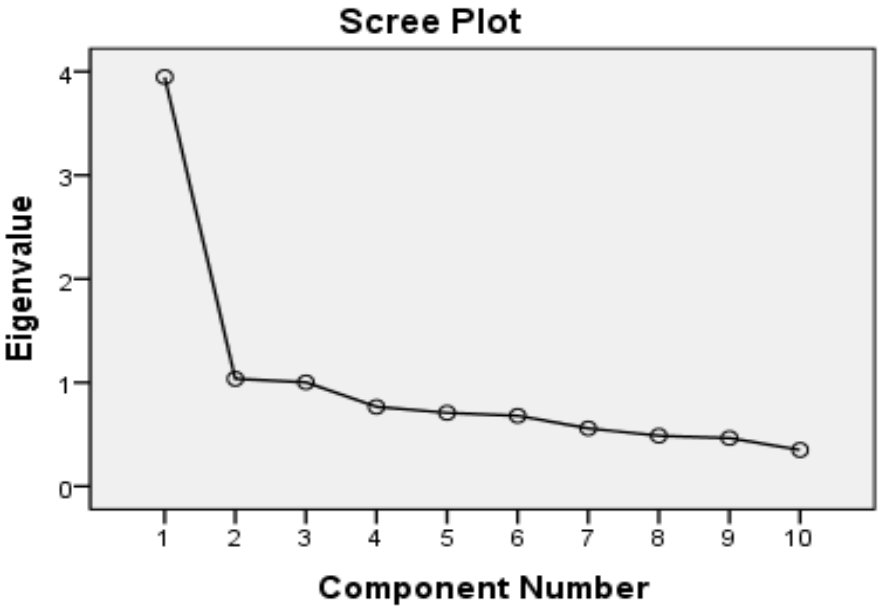
Mean	Variance	Std. Deviation	N of Items
43.3819	22.634	4.75756	10

Total Variance Explained

	Initial Eigenvalues			**Extraction Sums of Squared Loadings**			**Rotation Sums of Squared Loadings[a]**
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	3.947	39.475	39.475	3.947	39.475	39.475	3.293
2	1.036	10.365	49.840	1.036	10.365	49.840	2.657
3	1.003	10.027	59.866	1.003	10.027	59.866	2.018
4	.766	7.657	67.524				
5	.708	7.082	74.606				
6	.680	6.800	81.406				
7	.558	5.579	86.985				
8	.487	4.874	91.859				
9	.464	4.643	96.502				
10	.350	3.498	100.000				

Extraction method: principal component analysis.

Note: a. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.



Scree plot of attitude itemsComponent Matrix[a]

	Component		
	1	2	3
13. I make a difference to a person's day when I provide care with a palliative approach.	.780	-.050	.000
10. Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach.	.748	-.151	-.193
16. When I provide care with a palliative approach, I think about the whole person.	.712	-.284	-.144
14. I have an important role to play in pain assessment and management.	.651	-.308	-.241
1. A palliative approach can help a person's quality of life.	.622	.510	.015
6. Caring for a person with a palliative approach is rewarding.	.607	.179	.076
17. Privately sharing experiences with colleagues is important when providing a palliative approach.	.547	-.106	.469
4. Being aware of a person's emotional, social and spiritual needs is my responsibility.	.522	-.124	-.442
7. Providing a palliative approach based on an individual's wishes improves quality of life.	.576	.658	.042

11. I feel comfortable when an individual receiving a palliative approach says they are ready to die.	.438	-.291	.681

Extraction method: principal component analysis.

Note: a. 3 components extracted.

Pattern Matrix[a]

	Component	
	1	2
16. When I provide care with a palliative approach, I think about the whole person.	.777	-.025
14. I have an important role to play in pain assessment and management.	.749	-.074
10. Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach.	.699	.127
13. I make a difference to a person's day when I provide care with a palliative approach.	.644	.245
11. I feel comfortable when an individual receiving a palliative approach says they are ready to die.	.570	-.137
17. Privately sharing experiences with colleagues is important when providing a palliative approach.	.508	.097
4. Being aware of a person's emotional, social and spiritual needs is my responsibility.	.503	.069
7. Providing a palliative approach based on an individual's wishes improves quality of life.	-.075	.904
1. A palliative approach can help a person's quality of life.	.078	.768
6. Caring for a person with a palliative approach is rewarding.	.328	.417

Extraction method: principal component analysis.

Rotation method: Oblimin with Kaiser Normalization.[a]

Note: a. Rotation converged in 5 iterations

Structure Matrix

	Component	
	1	2
16. When I provide care with a palliative approach, I think about the whole person.	.766	.311
10. Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach.	.754	.430
13. I make a difference to a person's day when I provide care with a palliative approach.	.749	.523
14. I have an important role to play in pain assessment and management.	.717	.250
17. Privately sharing experiences with colleagues is important when providing a palliative approach.	.550	.317
4. Being aware of a person's emotional, social and spiritual needs is my responsibility.	.532	.286
11. I feel comfortable when an individual receiving a palliative approach says they are ready to die.	.511	.110
7. Providing a palliative approach based on an individual's wishes improves quality of life.	.316	.872
1. A palliative approach can help a person's quality of life.	.410	.801
6. Caring for a person with a palliative approach is rewarding.	.509	.559

Extraction method: principal component analysis.

Rotation method: Oblimin with Kaiser Normalization.

Appendix 12 Descriptive statistics

Descriptive statistics for final Knowledge items.

@7.Pleaseindicatehowlong youhavebeenworkinginthisrole	Mean	N	Std. Deviation	Minimum	Maximum	Range
1	13.49	88	2.501	4	17	13
2	13.52	116	2.455	3	17	14
3	14.03	144	1.918	8	17	9
Total	13.72	348	2.269	3	17	14

Descriptive statistics for final Skills items.

Report

7. Please indicate how long you have been working in this role	Mean	N	Std. Deviation	Minimum	Maximum	Range
1.00	10.80	87	2.587	2	13	11
2.00	10.96	115	2.194	3	13	10
3.00	11.38	141	2.160	4	13	9
Total	11.09	343	2.294	2	13	11

2-way ANOVA for final Skills items.

Tests of Between-Subjects Effects

Dependent Variable: Total/Final Skills Items

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	116.714[a]	17	6.866	1.326	.174
Intercept	19374.332	1	19374.332	3742.886	.000
@7.Pleaseindicatehowlongyou havebeenworkinginthisrole	4.070	2	2.035	.393	.675
@5.Whatisthehighestlevelof educationyouhavecompleted	69.140	5	13.828	2.671	.022
@7.Pleaseindicatehowlongyou havebeenworkinginthisrole * @5.Whatisthehighestlevelof educationyouhavecompleted	11.915	10	1.192	.230	.993
Error	1682.300	325	5.176		
Total	44009.000	343			
Corrected Total	1799.015	342			

Note: a. R Squared = .065 (Adjusted R Squared = .016)

Descriptive statistics for final Attitudes items.

7. Please indicate how long you have been working in this role	Mean	N	Std. Deviation	Minimum	Maximum	Range
1.00	8.47	85	1.666	0	10	10
2.00	8.54	116	1.696	1	10	9
3.00	9.05	142	1.251	2	10	8
Total	8.73	343	1.538	0	10	10

Tests of Between-Subjects Effects

Dependent Variable: Total Attitudes

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	7116.978	1	7116.978	2851.950	.000
	7.869	3.153	2.495[a]		
@7.Pleaseindicatehowlongyouhavebeenworkinginthisrole	5.564	2	2.782	1.462	.240
	114.215	60.034	1.903[b]		
@5.Whatisthehighestlevelofeducationyouhavecompleted	5.587	5	1.117	.708	.627
	23.457	14.865	1.578[c]		
@7.Pleaseindicatehowlongyouhavebeenworkinginthisrole * @5.Whatisthehighestlevelofeducationyouhavecompleted	12.982	9	1.442	.614	.785
	765.359	326	2.348[d]		

Tukey's post hoc test

Dependent Variable: Total Attitudes				
7. Please indicate how long you have been working in this role	5. What is the highest level of education you have completed?	Mean	Std. Deviation	N
1.00	1.00	10.00	.	1
	2.00	8.60	1.517	5
	3.00	8.78	.972	9
	4.00	8.26	1.937	46
	5.00	8.30	1.767	10
	6.00	8.93	.917	14
	Total	8.47	1.666	85
2.00	2.00	8.00	3.464	3
	3.00	8.56	1.365	16
	4.00	8.33	1.944	46
	5.00	8.88	1.366	26
	6.00	8.64	1.524	25
	Total	8.54	1.696	116
3.00	1.00	9.43	.535	7
	2.00	9.50	.577	4
	3.00	8.75	2.023	20
	4.00	9.12	1.029	41
	5.00	9.07	1.197	58
	6.00	8.83	1.030	12
	Total	9.05	1.251	142
Total	1.00	9.50	.535	8
	2.00	8.75	1.865	12
	3.00	8.69	1.607	45
	4.00	8.55	1.743	133
	5.00	8.94	1.318	94
	6.00	8.76	1.258	51
	Total	8.73	1.538	343

2-Way ANOVA for skills scores and factors: education and experience in role.

Tests of Between-Subjects Effects

Dependent Variable: Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	2350.803[a]	17	138.283	1.049	.405
Intercept	925425.311	1	925425.311	7018.018	.000
@5.Whatisthehighestlevelof educationyouhavecompleted	544.117	5	108.823	.825	.532
@7.Pleaseindicatehowlong youhavebeenworkinginthisrole	65.948	2	32.974	.250	.779
@5.Whatisthehighestlevelof educationyouhavecompleted * @7.Pleaseindicatehowlong youhavebeenworkinginthisrole	1355.858	10	135.586	1.028	.419
Error	43515.186	330	131.864		
Total	2073890.000	348			
Corrected Total	45865.989	347			

Note: a. R Squared = .051 (Adjusted R Squared = .002)

2-Way ANOVA for attitudes scores and factors: education and experience in role

Tests of Between-Subjects Effects

Dependent Variable: Total Attitudes

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	91.026[a]	17	5.354	1.140	.314
Intercept	36903.802	1	36903.802	7857.007	.000
@5.Whatisthehighestlevelofeducationyouhavecompleted	38.626	5	7.725	1.645	.148
@7.Pleaseindicatehowlongyouhavebeenworkinginthisrole	6.733	2	3.367	.717	.489
@5.Whatisthehighestlevelofeducationyouhavecompleted * @7.Pleaseindicatehowlongyouhavebeenworkinginthisrole	23.554	10	2.355	.501	.889
Error	1526.502	325	4.697		
Total	80512.000	343			
Corrected Total	1617.528	342			

Total Attitudes * 5. What is the highest level of education you have completed?

Total Attitudes						
5. What is the highest level of education you have completed?	Mean	N	Std. Deviation	Minimum	Maximum	Range
1.00	16.25	8	1.165	15	18	3
2.00	15.17	12	3.099	7	19	12
3.00	15.38	45	2.156	5	19	14
4.00	14.77	133	2.604	0	19	19
5.00	15.43	94	1.590	10	19	9
6.00	15.35	51	1.598	8	18	10
Total	15.17	343	2.175	0	19	19

Descriptive Statistics

Dependent Variable: Total Attitudes

5. What is the highest level of education you have completed?	7. Please indicate how long you have been working in this role	Mean	Std. Deviation	N
1.00	1.00	16.00	.	1
	3.00	16.29	1.254	7
	Total	16.25	1.165	8
2.00	1.00	15.40	2.702	5
	2.00	13.00	5.196	3
	3.00	16.50	.577	4
	Total	15.17	3.099	12
3.00	1.00	15.11	1.691	9
	2.00	15.56	1.632	16
	3.00	15.35	2.720	20
	Total	15.38	2.156	45
4.00	1.00	14.39	3.187	46
	2.00	14.67	2.692	46
	3.00	15.32	1.524	41
	Total	14.77	2.604	133
5.00	1.00	15.00	1.491	10
	2.00	15.31	1.379	26
	3.00	15.55	1.698	58
	Total	15.43	1.590	94
6.00	1.00	15.71	.726	14
	2.00	15.08	2.060	25
	3.00	15.50	1.168	12

	Total	15.35	1.598	51
Total	1.00	14.84	2.581	85
	2.00	14.98	2.273	116
	3.00	15.51	1.753	142
	Total	15.17	2.175	343

Appendix 13 final instrument

PANA_Knowledge Questionnaire

The purpose of these questions is to learn about your knowledge of a palliative approach. All questions concern the care of a person receiving a palliative approach and his/her family in the place where you provide care.

Instructions for completing the questionnaire

1. Please answer each question True, False or Don't Know
2. Please answer ALL questions

A palliative approach aims to improve quality of life when people have an illness or a condition that affects how long they will live.*	True	False	Don't Know
A palliative approach supports comfort but does not provide a cure.*	True	False	Don't Know
A palliative approach may be required for some people for months or years while for others it may be required for hours or days.*	True	False	Don't Know
The needs of people requiring a palliative approach are the same.	True	False	Don't Know
A palliative approach is offered when treatment will not help the person to live longer. *	True	False	Don't Know
People who have advanced cancer, severe lung or heart or kidney disease or advanced dementia benefit from a palliative approach. *	True	False	Don't Know
Families can often experience grief before the death of their family member. *	True	False	Don't Know
It is better to provide information about a palliative	True	False	Don't

approach to people from culturally and linguistically diverse backgrounds in English.			Know
The reason why a person receives nutrition through a Percutaneous Gastrostomy (PEG) tube (a feeding tube into the stomach) is because he/she can no longer swallow safely. *	True	False	Don't Know
Identifying symptoms (physical signs) is the first step in being able to manage symptoms. *	True	False	Don't Know
Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.*	True	False	Don't Know
When a person is receiving pain relief, they no longer feel pain.	True	False	Don't Know
Families or carers who know the person best are usually the first to detect changes in a person's condition. *	True	False	Don't Know
A person expressing a wish to die means that the person will die soon.	True	False	Don't Know
Bladder and bowel problems can cause discomfort when a person approaches the end of life.*	True	False	Don't Know
When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.*	True	False	Don't Know
Signs that death is near can be present hours to days before death occurs.*	True	False	Don't Know

PANA_Skills Questionnaire

The purpose of these statements is to learn about your skills when providing a palliative approach. All statements concern the care of a person receiving a palliative approach and his/her family in the place where you provide care.

Instructions for completing the questionnaire

1. For each statement, choose ONE option that best describes your ability.
1. Please respond to ALL statements.

Observe what a person can do without assistance.	I know how to do this	Unsure	I don't know how to do this
Assist in updating care plans.	I know how to do this	Unsure	I don't know how to do this
Direct families to other members of the care team when they need further advice.	I know how to do this	Unsure	I don't know how to do this
Care for a person with challenging behaviours.	I know how to do this	Unsure	I don't know how to do this
Raise the concerns of (advocate for) the individuals in my care.	I know how to do this	Unsure	I don't know how to do this
Observe for pain using a valid and reliable pain assessment tool.	I know how to do this	Unsure	I don't know how to do this
Provide non-medication strategies, such as gentle massage, in order to manage pain.	I know how to do this	Unsure	I don't know how to do this
Evaluate the effectiveness of pain management strategies using a validated pain assessment tool.	I know how to do this	Unsure	I don't know how to do this
Contribute to problem solving to seek solutions.	I know how to do this	Unsure	I don't know how to do this
Recognise the signs when an	I know how	Unsure	I don't know

individual is in the last days or hours of life.	to do this		how to do this
Attend to a dying individual's care.	I know how to do this	Unsure	I don't know how to do this
Find ways to cope with my own emotional responses when a person I have been caring for has died.	I know how to do this	Unsure	I don't know how to do this
Reflect on what I say and do when providing a palliative approach.	I know how to do this	Unsure	I don't know how to do this

PANA_Attitudes Questionnaire

The purpose of these statements is to learn how nursing assistants feel providing a palliative approach. All questions concern the care of a person receiving a palliative approach and his/her family in the place where you provide care.

Instructions for completing the questionnaire

1. Please indicate how much you agree or disagree with each of the following statements.
2. Please respond to ALL statements.

A palliative approach can help a person's quality of life.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Being aware of a person's emotional, social and spiritual needs is my responsibility.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Caring for a person with a palliative approach is rewarding.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Providing a palliative approach based on an individual's wishes improves quality of life.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Understanding physical and emotional changes at the end of life helps me provide care with a palliative approach.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree

I feel comfortable when an individual receiving a palliative approach says they are ready to die.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I make a difference to a person's day when I provide care with a palliative approach.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I have an important role to play in pain assessment and management.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
When I provide care with a palliative approach, I think about the whole person.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Privately sharing experiences with colleagues is important when providing a palliative approach.	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree

Scoring

Scoring	**Correct/positive response = 1 point**	**Total**
PANA_Knowledge Questionnaire	True* False items: 4, 11, 15, 19	17
PANA_Skills Questionnaire	I know how to do this	13
PANA_Attitudes Questionnaire	1= Strongly Agree/Agree 0= Unsure/Disagree/Strongly Disagree	10
Total		40